S. Hrg. 101-713, Pt. 4

# DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1991

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## HEARINGS

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES SENATE

ONE HUNDRED FIRST CONGRESS

SECOND SESSION

ON

## H.R. 5257

AN ACT MAKING APPROPRIATIONS FOR THE DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES, FOR THE FISCAL YEAR ENDING SEPTEMBER 30, 1991, AND FOR OTHER PURPOSES

**Part 4 (Pages 1–732)**

**Nondepartmental witnesses**

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# DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1991

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THURSDAY, MARCH 29, 1990

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
*Washington, DC.*

The subcommittee met at 9:40 a.m., in room SD-116, Dirksen Senate Office Building, Hon. Tom Harkin (chairman) presiding.

Present: Senator Harkin.

## NONDEPARTMENTAL WITNESSES

Senator HARKIN. Good morning. The subcommittee will come to order. This morning we continue with the last of 6 days of public witness testimony focusing on programs funded by the Subcommittee on Labor, Health and Human Services, Education and 20 related agencies.

During these several sessions, the subcommittee will hear testimony from about 150 witnesses. We do regret to all the members of the subcommittee that we have had to limit the number of witnesses. I think we had requests for over 300 and there is no possible way that we can do that, but we have said that anyone who has their testimony to us by April 9 will have that testimony put into the hearing record.

So, we are going to try to use the red light, green light system if we can. That works better in the breach than in the actual performance of it.

### STATEMENT OF HON. PAUL SIMON, U.S. SENATOR FROM ILLINOIS

Senator HARKIN. I would like to welcome all of the witnesses. The first is my distinguished colleague from the State of Illinois, Senator Paul Simon for whom I have both the greatest respect and admiration and also friendship. Senator Simon and I came to the Congress together in 1974 and the Senate in 1984 and Senator Simon has been a great advocate for Human Service Programs, especially education, Education of the Disabled, Public Law 94-142, and he has been one of the first initiators of that law back in 1975 fresh from Congress. So, a long and distinguished career and one that I know is going to be long and distinguished in the future too, and I am glad you are here.

Senator SIMON. Thank you very much, Mr. Chairman. I am pleased to be here and pleased to be—and he has nothing to do with my testimony, so I do not want to inflict that on him, but Tony Randall has helped on so many good causes and it is good to have him here.

I am here specifically on two things, but let me just add one other point that I am here, because I just ran into some people who are testifying or who are interested in one other thing.

First, on the JTPA Program. We are reauthorizing and revising the JTPA Program to take care of some of the abuses and to, frankly, stop some of the creaming that has taken place. Specifically what we want to do is focus more on the hard to employ. It is very interesting, you know we are spending a lot of time making speeches about drugs. NIH came before our subcommittee not too long ago with the latest statistics on what ethnic group and age group and so forth are using drugs. The group that uses drugs the most are the unemployed. I said to the director, you mean, if we work on the problems of unemployment, we are working on the problems of drug abuse. He said, no question about it.

Specifically what we are asking for is an increase of $252 million in the title II, that is for the poor and the hard to employ for the youth, and $130 million there for adults.

The second area, one that I know is of great interest to you, where the Senate passed 99 to zero, a literacy program. What we really ought to do is to move on this problem and it is tied in with the unemployment problems and these other problems too. It is interesting, the person who testifies more about illiteracy before our committee is not the Secretary of Education, but the Secretary of Labor who says over and over again, we cannot get people who are—to get employed who do not have basic skills.

After World War II, the average person needed a fourth grade education to work. Today, the average worker has a ninth grade education and it is going up. We just cannot tolerate a nation with 23 million functionally illiterate adult Americans; 4 million of whom cannot read their name in block print; 19 million of whom cannot read a newspaper headline. They just cannot function effectively; 75 percent of the people who are unemployed more than 5 weeks are functionally illiterate.

So if we could, ideally the authorization we passed in the Senate, and I think it is going to pass the House, and I would certainly expect it to be signed by the President, will authorize $225 million.

Senator HARKIN. That is for illiteracy.

Senator SIMON. That is for illiteracy. Adult illiteracy and what I think we would want at a minimum is $130 million.

Senator HARKIN. $130 million increase?

Senator SIMON. That is right. Ideally, I have to say the full authorization $225 million, and this is a program that pays off rapidly. You know there are a lot of programs like preschool education take years to pay off. But literacy, almost immediately when people learn how to read and write. I could tell you the stories of the individuals, I cannot give you the statistics, but immediately people—it is Mary Blandon in Chicago, who was living in the Chicago Housing Authority on welfare, mother of 12, grandmother of 24. She learned how to read and write. Now she has a job. Now she is a homeowner. Now she is teaching those grandchildren how to read and write. Those are the things that we have to do.

### PREPARED STATEMENT

And then finally, and this is not part of my testimony, I just ran into these people who were here from the Alliance for the Mentally Ill, anything we can do in this area. Frankly, this is an area where people have not stood up in the past. If your relative or someone in your family has cancer or arthritis or diabetes we stand up and we say we have got to do something about it. Mental illness, we treat it as a matter of shame. So we have not moved as a nation on this problem as we should. I do not know what specifically is before you right now, but this is an area, also, frankly, we ought to be doing something about.

That is the end of my testimony. Any tough questions you have, refer them to Tony Randall.

[The statement follows:]

## STATEMENT OF SENATOR PAUL SIMON

MR. CHAIRMAN, AND MEMBERS OF THE SUBCOMMITTEE, IT IS A PRIVILEGE FOR ME TO APPEAR BEFORE THIS DISTINGUISHED SUBCOMMITTEE. I AM TESTIFYING TODAY TO REQUEST YOUR SUPPORT TO INCREASE FUNDS FOR IMPORTANT JOB TRAINING AND LITERACY EDUCATION PROGRAMS THAT MAKE A TREMENDOUS DIFFERENCE IN THE LIVES OF MILLIONS OF PEOPLE WHO ARE THE FUTURE OF THIS NATION. I AM SPEAKING ON BEHALF OF THE POOR, THE UNEMPLOYED, AND THE ILLITERATE -- CONSTITUENCIES WHO MAY NOT VOTE, LOBBY, OR SPEAK FOR THESE PROGRAMS, WHICH ARE AT LEAST AS CRITICAL TO OUR LONG TERM ECONOMIC SECURITY, AND THEREFORE, OUR NATIONAL SECURITY, THAN MANY OF OUR DEFENSE PROGRAMS.

AS CHAIRMAN OF THE SUBCOMMITTEE ON EMPLOYMENT AND PRODUCTIVITY, I HAVE BECOME INCREASINGLY CONCERNED ABOUT OUR NATION'S MOST DISADVANTAGED CITIZENS, AND OUR YOUTH IN PARTICULAR, WHO LACK THE BASIC SKILLS NEEDED TO FIND AND KEEP JOBS TO SUPPORT THEMSELVES AND THEIR FAMILIES. WE ALL KNOW THE STATISTICS, AND THEY ARE SHOCKING. SOME 23 MILLION AMERICANS ARE CONSIDERED FUNCTIONALLY ILLITERATE. ABOUT 29% OF OUR HIGH SCHOOL YOUTH ARE DROPOUTS. THE AVERAGE AMERICAN HIGH SCHOOL GRADUATE SEEKING A JOB READS AT THE LEVEL OF AN AVERAGE EIGHTH GRADER. ONE FOURTH OF THESE GRADUATES READ AT THE SIXTH GRADE LEVEL.

THESE STATISTICS CARRY WITH THEM FRIGHTENING IMPLICATIONS FOR OUR NATION'S ECONOMIC SECURITY AND PROSPERITY. AS WE MOVE INTO THE 21TH CENTURY, WE MUST ACKNOWLEDGE THAT THE WORKFORCE OF TOMORROW WILL BE VERY DIFFERENT THAN THAT OF TODAY. SINCE WORLD WAR II THE EDUCATIONAL THRESHOLD FOR THE AVERAGE ENTRY LEVEL POSITION HAS RISEN FROM THE FOURTH GRADE LEVEL TO A MINIMUM TWELVE GRADE LEVEL. DESPITE WORK SHORTAGES IN SOME AREAS, FEW JOBS WILL BE AVAILABLE TO THOSE WHO ARE UNSKILLED. INDEED, THE PERSON WHO CANNOT READ, WRITE, AND COMPUTE WILL BE EFFECTIVELY DISENFRANCHISED FROM THE LABOR FORCE ALTOGETHER.

AS PART OF THE NATIONAL INVESTMENT IN OUR NATION'S ECONOMIC FUTURE, I URGE YOU TO APPROVE INCREASED APPROPRIATIONS IN FY91 FOR TITLE II OF THE JOB TRAINING PARTNERSHIP ACT (JTPA). JTPA IS A FEDERAL, STATE AND LOCAL PARTNERSHIP PROGRAM TO TRAIN DISADVANTAGED ADULTS AND YOUTH. TITLE II IS THE PRIMARY FEDERAL PROGRAM DESIGNED TO TRAIN THE POOR AND HARD-CORE UNEMPLOYED FOR JOBS AND LONG-TERM EMPLOYMENT.

AS YOU KNOW, LAST YEAR I INTRODUCED S. 543, THE JOB TRAINING AND BASIC SKILLS ACT. THESE AMENDMENTS ARE INTENDED TO REVISE AND RESTRUCTURE JTPA TO MAKE IT THE BEST JOB TRAINING PROGRAM IN OUR COUNTRY'S HISTORY. A MAJOR FOCUS OF S. 543 IS TO IMPROVE THE TARGETING OF JTPA RESOURCES AND SERVICES TO THE MOST NEEDY AND LEAST JOB READY INDIVIDUALS -- THOSE WHO SUFFER MULTIPLE BARRIERS TO EMPLOYMENT. THE ADDITIONAL TARGETING REQUIREMENTS IN S. 543 SHOULD LAY TO REST THE PROBLEM OF "CREAMING" IN JTPA -- CHARGES THAT HAVE PLAGUED THIS PROGRAM SINCE ITS INCEPTION.

MR. CHAIRMAN, IN ADDITION TO REFOCUSING THE JTPA SYSTEM ON THE NEEDIEST INDIVIDUALS, MY BILL WILL ALSO REQUIRE MORE INTENSIVE, AND THEREFORE COSTLY, TRAINING INTERVENTIONS. I WANT TO MOVE THE SYSTEM AWAY FROM HIGH TURNOVERS AND QUICK PLACEMENTS -- TO COMPREHENSIVE BASIC SKILLS AND VOCATIONAL TRAINING, WHICH IMPACT ONE'S LONG-TERM INCOME EARNING POTENTIAL. AS A RESULT OF THE LONGER, MORE INTENSIVE SERVICES THAT WILL BE PROVIDED TO EACH JTPA PARTICIPANT UNDER S. 543, MORE FUNDING WILL BE REQUIRED SIMPLY TO MAINTAIN CURRENT NUMBER OF PARTICIPANTS IN THE TITLE II PROGRAM.

RECOGNIZING THIS NEED, THE ADMINISTRATION HAS PROPOSED A $252 MILLION INCREASE FOR THE TITLE II YOUTH PROGRAM AND A NEW FAIR CHANCE YOUTH INITIATIVE AUTHORIZED IN S. 543. I STRONGLY SUPPORT THIS REQUEST AND STRONGLY URGE YOU TO APPROVE IT. IT IS IMPORTANT TO NOTE, HOWEVER, THAT EVEN WITH THIS INCREASE, THERE WILL BE A DECLINE IN THE NUMBER OF YOUNG PEOPLE PARTICIPATING IN JTPA PROGRAMS. ANOTHER $180 MILLION WOULD BE NEEDED TO MAINTAIN PROJECTED FY1990 LEVELS OF PARTICIPATION. SIMILARLY, THE TITLE II ADULT PROGRAM WILL REQUIRE ADDITIONAL RESOURCES - WE ESTIMATE $130 MILLION - JUST TO MAINTAIN THE PROJECTED

FY 1990 NUMBER OF ADULT PARTICIPANTS. I URGE YOU TO PROVIDE A SUBSTANTIAL INCREASE TO MEET THE NEEDS OF BOTH PROGRAMS.

IN REAL TERMS, JTPA HAS BEEN ONE OF THE FEDERAL PROGRAMS HARDEST HIT WITH LOST PURCHASING POWER DURING THE 1980s. IN FY90, THE JTPA BUDGET IS LESS THAN ONE-THIRD OF WHAT WAS SPENT ON CETA; IN FY90, THE JTPA TITLE II PROGRAM RECEIVED FEWER FUNDS THAN IN ITS FIRST YEAR OF OPERATION!

MR. CHAIRMAN, I KNOW THAT YOU HAVE HAD A PARTICULAR INTEREST IN SOME REPORTS OF ABUSES IN THE JTPA PROGRAM RELATED TO CERTAIN CONTRACTING PROCEDURES AND THE USE OF ON-THE-JOB TRAINING CONTRACTS. I WANT YOU TO KNOW THAT I AND MY STAFF HAVE LOOKED INTO THESE MATTERS EXTENSIVELY. I BELIEVE THAT S. 543 WILL IMPROVE FISCAL ACCOUNTABILITY IN JTPA AND PREVENT CONTRACTING ABUSES IN THE FUTURE. IN ADDITION, I AM REVIEWING THIS MATTER TO ENSURE THAT THE FEDERAL RESOURCES INVESTED IN THIS PROGRAM ARE SPENT EFFICIENTLY AND EFFECTIVELY.

JTPA IS A PROGRAM THAT IS UNIQUELY POSITIONED TO DEAL WITH THE WIDENING GAP BETWEEN THE INCREASING SUPPLY OF UNSKILLED (AND OFTEN UNEDUCATED) LABOR AND THE DECREASING DEMAND FOR UNSKILLED LABOR. THERE IS A CRITICAL NEED TO FOCUS, IN PARTICULAR, ON OUR NON-COLLEGE BOUND YOUTH WHO HAVE BECOME "THE FORGOTTEN HALF". THESE YOUTH TOO OFTEN FALL BETWEEN THE CRACKS IN THE TRANSITION FROM SCHOOL TO WORK. YET, THE FEDERAL INVESTMENT IN THEIR WELFARE IS PITIFULLY SMALL. WE SPEND, FOR EXAMPLE, ONLY ABOUT $1800 FOR FOUR MONTHS OF TRAINING FOR THE AVERAGE YOUTH PARTICIPANT IN JPTA. THIS COMPARES TO AN AVERAGE PUBLIC AND PRIVATE SUBSIDY OF ABOUT $5000 THAT EACH STUDENT ENROLLED IN HIGHER EDUCATION CAN EXPECT TO RECEIVE EACH YEAR IN SCHOLARSHIPS AND GRANTS. MR. CHAIRMAN, I SUPPORT A STRONG FEDERAL INVESTMENT IN HIGHER EDUCATION FOR ALL AMERICANS. BUT, WE SIMPLY MUST DO BETTER FOR THOSE YOUNG AMERICANS WHO DO NOT GO ON TO COLLEGE, BUT ARE INADEQUATELY PREPARED FOR THE WORKPLACE. WE DESPERATELY NEED THEIR UNTAPPED TALENT AND PRODUCTIVITY IF OUR NATION IS TO BECOME COMPETITIVE IN THE WORLD MARKETPLACE.

AS ONE MEMBER OF THE JTPA ADVISORY COMMITTEE TO LABOR SECRETARY DOLE COMMENTED: "THE JOB TRAINING PARTNERSHIP ACT IS SOMETIMES CALLED THE SECOND CHANCE SYSTEM, SOMETIMES CALLED THE LAST CHANCE SYSTEM. FOR SOME AMERICANS IT IS THE ONLY CHANCE THEY HAVE TO BECOME THE PRODUCTIVE CITIZENS THAT THEY WISH TO BE AND THAT OUR COMMUNITIES, OUR ECONOMY AND OUR COUNTRY NEEDS THEM TO BE."

MR. CHAIRMAN, OUR NATION'S ECONOMIC PROSPERITY ALSO DEPENDS ON COMBATTING ILLITERACY. THIS YEAR IS THE INTERNATIONAL YEAR OF ILLITERACY AND SHOULD MARK THE BEGINNING OF A MAJOR CAMPAIGN TO WIPE OUT ILLITERACY BY THE YEAR 2000. MY BILL, S. 1310, THE NATIONAL LITERACY ACT PROVIDES THE BLUEPRINT AND THE STRUCTURE FOR A SUSTAINED FEDERAL EFFORT IN THIS REGARD. AS YOU KNOW, S. 1310 PASSED THE SENATE BY A UNANIMOUS VOTE IN FEBRUARY. I ANTICIPATE THAT THE HOUSE WILL ACT THIS SPRING.

I HOPE THAT THIS SUBCOMMITTEE WILL TAKE A HARD LOOK AT HOW WE CAN BEGIN A SERIOUS ANTI-LITERACY CAMPAIGN THIS YEAR. SPECIFICALLY, I URGE YOU TO PROVIDE THE $100 MILLION INCREASE PROPOSED IN S. 1310 FOR BASIC STATE GRANTS UNDER THE ADULT EDUCATION PROGRAM. THE ADULT EDUCATION ACT IS THE PRIMARY FEDERAL PROGRAM AIMED AT COMBATTING ILLITERACY IN OUR COUNTRY; YET, IT SERVES LESS THAN 9% OF THE NEEDY ILLITERATE POPULATION. MOREOVER, I URGE YOU TO APPROVE A MODEST AMOUNT OF $35 MILLION FOR FOUR SMALL, BUT CRITICALLY IMPORTANT, NEW PROGRAMS ESTABLISHED UNDER S. 1310: A NATIONAL CENTER FOR LITERACY, STATE LITERACY RESOURCE CENTERS, A FAMILY LITERACY PROGRAM, AND LITERACY CHALLENGE GRANTS.

MR. CHAIRMAN, IN CLOSING, LET ME JUST ADD THAT EDUCATION AND TRAINING FOR THE POOR AND HARD-CORE UNEMPLOYED IS NOT JUST GOOD POLICY AND A GOOD LONG-TERM INVESTMENT -- IT ALLOWS US TO FIGHT DRUG ABUSE IN OUR COUNTRY. RECENT SURVEYS BY THE NATIONAL INSTITUTE ON DRUG ABUSE ON ILLICIT DRUG USE BY A VARIETY OF AGE AND DEMOGRAPHIC CHARACTERISTICS HAS PROVIDED SOME STARTLING INFORMATION. THE HIGHEST USE OF DRUGS WAS

NOT IN URBAN AREAS, OR AMONG YOUTH, MINORITIES OR DROPOUTS -- IT WAS AMONG THE UNEMPLOYED. CLEARLY, A FEDERAL CRIME AND ANTI-DRUG STRATEGY MUST INCLUDE A FOCUS ON JOBS AND JOB TRAINING FOR THE UNEMPLOYED. WHEN WE DISCUSS CRIME AND DRUG CONTROL, WE CANNOT FORGET THAT 90% OF ALL PRISONERS ARE BACK ON THE STREET IN LESS THAN TEN YEARS.

MR. CHAIRMAN, I BELIEVE THAT THERE ARE NO ISSUES MORE IMPORTANT THAN EDUCATING AND TRAINING PEOPLE SO THAT THEY CAN REACH THEIR FULL POTENTIAL. AS A MEMBER OF THE SENATE BUDGET COMMITTEE, I AM WORKING HARD TO ENSURE THAT THE FY1991 BUDGET RESOLUTION INCLUDES AMPLE RESOURCES IN FUNCTION 500 SO THAT YOUR SUBCOMMITTEE WILL HAVE THE FLEXIBILITY TO INVEST IN EDUCATION AND TRAINING. THE TIME IS RIPE FOR A "PEACE DIVIDEND" AND I HAVE PROPOSED THAT DEFENSE SPENDING BE REDUCED BY ABOUT $20 BILLION BELOW FY1991 CURRENT SERVICES LEVELS, WITH A SIGNIFICANT SHARE OF THOSE RESOURCES TO BE DEVOTED TO EDUCATION AND TRAINING PROGRAMS. AN IMPORTANT PART OF MY BUDGET PROPOSAL ALSO INVOLVES A MEANINGFUL REDUCTION IN THE FEDERAL DEFICIT. BUT, TODAY, I WOULD LIKE TO EMPHASIZE THE NEED TO ADDRESS OUR NATION'S SOCIAL DEFICIT. I URGE YOU TO PROVIDE THE LEADERSHIP NEEDED SO THAT EVERY AMERICAN WILL HAVE THE OPPORTUNITY TO LEARN TO READ AND WRITE, TO OBTAIN A GOOD EDUCATION, AND TO HOLD A DECENT JOB.

THANK YOU, MR. CHAIRMAN AND MEMBERS OF THE SUBCOMMITTEE, FOR THIS OPPORTUNITY TO PRESENT MY VIEWS ON JOB TRAINING AND LITERACY PROGRAMS. I WOULD BE PLEASED TO ANSWER ANY QUESTIONS THAT YOU MAY HAVE.

Senator HARKIN. Thank you very much. Now give me those figures again.

Senator SIMON. JTPA on title II here, what we would really like here is $252 million increase for the youth program part of it and $130 million for the adult. This to train the hard to employ. Again, it is a little like the literacy program. You train these people who are hard to employ and they are going to be taxpayers instead of tax spenders. It is one of those things that really pays off.

Senator HARKIN. Again the point you make about it being an immediate payoff is important. This is immediate payoff. What again did you say? You said a percentage of people that are unemployed that are functionally illiterate?

Senator SIMON. Some 75 percent of those who are unemployed more than 5 weeks are functionally illiterate. The majority of the people in our prisons today are functionally illiterate. It is no accident that the people who get into trouble cannot function in our society. Eleanor Holmes Norton said about our drug program, I am trying to think of the precise phrase she used, but she said we are great on capturing prisoners, but we are not very good on helping the wounded. And that is kind of where we are in our society. What we have to do is to get people before they get into prison and give them an option and say, we are going to give you a spark of hope. The great division in our society is not between black and white, between Hispanic and anglo, or even between rich and poor. It is between people who have hope and people who do not. What we have to do is give people a spark of hope.

Senator HARKIN. Paul, thank you very much. You are very eloquent and very forceful. All I can tell you is we are trying to get our 302(b) allocation as high as possible.

Senator SIMON. Let me just add I am working on that. I am going to be proposing in the Budget Committee that we take a 3-percent cut from Defense, where it is right now, 3 percent down, not 3 percent from the current services, but 3 percent down, that one-half of that go for—that is about a $9 billion cut, that one-half of that go for reducing the deficit and the other one-half go for education and the kind of programs that we are talking about here.

Senator HARKIN. If you could get that done, we are rounding third base and coming to home, if you can get that done.

Senator SIMON. I am not sure we can get it done, but I think it is worth fighting for, and frankly, if we do not get it done in the committee, I think we ought to fight for it on the floor.

Senator HARKIN. I am with you.

Senator SIMON. Last time I had a proposal for a 1-percent cut, this is after this agreement had been reached between the White House and all of the leaders, I asked for a 1-percent cut in defense, shifting it over to education. It would have been a 15-percent increase in education. Despite the fact that we had the leadership and everybody else, you know all the hierarchy against us, we picked up 34 votes, as I recall, on that. We did amazingly well. I think the public understands we are in a different world today than we were 1 year ago, and we ought to be shifting our priorities.

Senator HARKIN. Well, I was with you on it, and I will be with you on it again. Thank you, Paul, thank you very much.

## STATEMENT OF DR. GLORIA REICH, AMERICAN TINNITUS ASSOCIATION

ACCOMPANIED BY:
TONY RANDALL
CARL ROSS

Senator HARKIN. Gloria Reich and Carl Ross? Well, let us see, we only have one microphone. We are extremely pleased to have with us this morning Dr. Gloria Reich, Tony Randall, and Carl Ross to speak on behalf of the American Tinnitus Association, which I used to always call tinnitus until I learned how to pronounce it. Well, look who is here. Governor Perpich of Minnesota, meet Tony Randall.

Mr. RANDALL. If I lived there, I would vote for you.

Governor PERPICH. We can arrange that.

Senator HARKIN. We are delighted to have Tony Randall here. As you know, Mr. Randall has had a long distinguished career as a performing artist in America, both on screen and on stage. I just had a nice conversation with him before about something I had not been aware of which I will not even go into the record on right now. In American theater, classical theater, well, as I said, I will not get into that. That is not the subject of this hearing.

I am always pleased when someone of his stature and public acclaim takes an interest in the work of this subcommittee and some of the problems that confront us in this country. Sometimes these various illnesses or afflictions do not get much publicity or get much recognition unless someone like Mr. Randall steps forward and talks about it and focuses public attention on it. So we are really pleased that you would take time from your work and fly down from New York today to be here to tell us about the American Tinnitus Association and your own views on what we ought to be doing, what you want us to know about tinnitus and why should we be focusing on it.

I welcome you. How do you want to proceed?

Ms. **Reich**. Good morning. I am Gloria Reich and we are representing the 12 million Americans who have severe tinnitus that is severe enough to be disabling their lives. About 20 percent of the population has tinnitus at one time or another, but for most of the people it is not a large problem. We would like you to hear just a few seconds of some synthesized sounds of tinnitus and then Tony Randall will speak for us.

Senator **Harkin**. You explain what I am listening to here.

### STATEMENT OF TONY RANDALL

Mr. **Randall**. Thank you, Senator. First, I should thank Senator Simon for saying such nice things about me. He said that I have been known to support various good causes and I believe that is true, but this is the first one that I have become involved in that actually afflicts me. I am a sufferer from what Gloria Reich calls tinnitus and what you call tinnitus. Either is correct.

Senator **Harkin**. Thank you. Actually I will go back to tinnitus because that sounds better.

Mr. **Randall**. Well, any word ending itus seems to mean a inflammation. But whether it is an actual inflammation of the ear, we do not know. Almost nothing is known about it except that we suffer from it. It is a ringing in the ears. A noise in the ears. A permanent, unending distraction, and in some cases, an affliction that can lead to madness and suicide. That is why it is really an important thing.

I am a lucky sufferer. Mine is mild and I can live with it. When I first had it, I thought I would go crazy and I went from doctor to doctor and had every sort of treatment. None of them worked. And I do not know if there is a cure. In fact, I know there is no cure. There is treatment, but there is not a cure.

Every doctor finally told me, Tony, you are going to have to learn to live with it. And I live with it. I have actually reached the point where I do not think of it much. But I do think of it, and at times it gets louder. Mine is not a ringing. Mine is a high hissing. In some cases it is a deafening ringing and in one very famous case, the composer, Smetena, it was a permanent high E, a very high E on the violin. It did not change, he just heard a high E until he went crazy. It will drive you crazy.

I bring you greetings from David Letterman, who has authorized me to tell you he is also a sufferer. As Gloria said, there are millions of us. It is a serious problem when it leads to madness or death or when it so cripples a person that he cannot function as a human being anymore. If it is loud enough, you cannot function. You will simply go crazy with it when there is nothing in the world you can do about it. It does not always interfere with hearing. It does not always seem to have that much to do with hearing. You hear a noise, but your hearing otherwise is unimpaired. In Gloria's case, she is also hearing impaired and has tinnitus. Mine is just a constant noise that is, I say, I can live with.

### PREPARED STATEMENT

What it always comes down to, of course, in all of these things is money. There are insufficient funds for research. Almost no one knows anything about this particular condition. We hope, of course, the day will come when we can do enough research to cure it. And with that, and my good wishes, and good wishes to every sufferer, I will sign off.

[The statement follows:]

## STATEMENT OF DR. GLORIA REICH, AMERICAN TINNITUS ASSOCIATION

My name is Gloria Reich and I am the Executive Director of the American Tinnitus Association. I would like to take this opportunity to thank our volunteer, Carl Ross, who has worked with your committee staff, and with Senator Moynihan and his staff to bring us to this day.

Our special guest today, Tony Randall, has acknowledged his own tinnitus in the media and has provided ATA with an excellent series of Public Service Announcements to help educate the public about tinnitus. He will tell you more after we listen briefly to these synthesized sounds of tinnitus.

ATA has been in existence since 1971 informally and has been incorporated since 1979. I have seen the organization grow from providing services to 125 people at the beginning of 1976 to more than 175,000 people today. More than 30,000 people contribute to ATA, supporting our goals of research and education about tinnitus and other hearing disorders. Each year more than a quarter million of our brochures help to educate the public about tinnitus prevention, noise which can damage the ears, coping with tinnitus, hyperacusis (a condition sometimes called super-sensitive hearing), demographics of tinnitus sufferers, and other topics. ATA has more than one-hundred self-help and support groups throughout the country. Our constituency overlaps the hard of hearing and deaf communities as well as the normal hearing public.

Mr. Chairman, on behalf of more than 50 million people who have tinnitus and especially the 12 million people who suffer from 'severe' tinnitus, I appreciate the opportunity to be with you today to share some concerns and recommendations related to the National Institute on Deafness and Other Communication Disorders (NIDCD); to the costs of tinnitus to our society, and to the education and treatment of people with tinnitus and other hearing disorders.

We know and appreciate the budgetary constraints facing the new institute and the competition for the available funds. Tinnitus is probably the singlemost distressing condition associated with hearing loss and yet it is poorly understood and poorly treated. Even in the advisory boards and councils of the new institute there are no representatives whose specialty is tinnitus.

Because of this long history of neglect and the desperate need to "catch-up", now is the time to address this invisible, but distressing problem. We urge you to approve the $165,000,000 NIDCD budget and ask that you set aside 20 to 30 million dollars for the study of tinnitus.

Modest research projects over the past decade have produced promising results. Armed with this knowledge NIDCD can instigate research designed to learn much more about tinnitus and to produce clinical measures to benefit sufferers now. Some areas that should be investigated include:

1) The evaluation and refinement of therapeutic processes.

   At present the promising therapies for tinnitus include the use of masking (substitution of a more acceptable sound for the patient's internal noise); hearing-aids (which produce a kind of masking by making it possible for the person to hear environmental sounds); biofeedback and other psychological interventions which have been helpful in teaching some patients how to adjust to their affliction.

2) Search for and identify underlying mechanisms of tinnitus. Current studies using state-of-the-art imaging techniques are leading towards an objective test for tinnitus. Currently tinnitus presence is subjective, which, particularly in litigation, generates inadequate identification of the condition.

3) Develop both behavioral and physiological animal models for tinnitus. Current studies at Yale University (NIH funded), are directed toward animal model development.

4) Better understand the relationship between various drugs and tinnitus drugs (a variety of drugs are routinely prescribed for tinnitus patients to help them control their anxiety, depression, vascular disorders, and a host of others used in somewhat of a hit-and-miss fashion), unfortunately, some of these drugs have severe side effects -- not the least of which is the worsening of the person's tinnitus. Current studies of ototoxic drugs at the Oregon Hearing Research Center have produced valuable insights regarding drugs and tinnitus.

5) Better understand the relationship between dental anomalies and tinnitus. A small research project, funded by ATA, at the TMJ Foundation seeks to establish these relationships.

6) Develop effective, standardized clinical measures of tinnitus sensation. The Tinnitus Data Registry of the Tinnitus Clinic in Oregon, funded originally by ATA, then by NIH, and currently by the Department of Education, has provided excellent information on more than 5000 patients.

7) Develop or refine present measures of tinnitus severity and psychological consequences. Several individual researchers have provided information that can be used as a basis for this development.

In order to achieve these goals, ATA recommends the establishment of tinnitus clinical research programs at the new regional research centers of the NIDCD. This research must be interdisciplinary. Tinnitus does not belong solely to one specialty. In order to move forward there must be involvement by otolaryngologists, otologists, audiologists, psychologists, dentists, neurologists, engineers and many others.

8) Initiate prevalence studies for tinnitus in the general population utilizing information already available from existing tinnitus surveys conducted on segments of the tinnitus population. The prevalence figures currently cited have been derived from a study published in 1968 by the National Center for Health Statistics. Questions in the present Census bureau's National Health Interview are woefully inadequate to provide comprehensive statistics about tinnitus. Incidence estimates are not available at all because tinnitus is not a "reportable" condition (unlike scarlet fever or AIDS). Without prevalence studies we cannot correctly estimate society's costs and without incidence reports we cannot know the extent to which tinnitus is increasing.

9) Initiate public awareness programs to control noise exposure, particularly directed toward the school-age population. Prevention is our only weapon until we have the ability to cure tinnitus. It is likely that people will always be afflicted with tinnitus, the realities of modern life are such that people cannot avoid either noise or stress, circumstances which often lead to tinnitus. People must be educated about the damage noise can do. An astonishing number of musicians, for example, are now reporting severe tinnitus and hearing deficits. Industry

standards for noise are also inadequate to protect ears rendered sensitive by environmental noise exposure.

Tinnitus is not considered a life threatening condition. That statement is of little comfort to the sufferer who can no longer concentrate at work or maintain pleasant social relationships with family, friends and colleagues. It is of even less comfort to the family of a sufferer who has committed suicide because of the incessant noise.

There are organized tinnitus associations in England, Canada, Australia, Japan, Germany, Spain, France, New Zealand, Italy, and Israel, but people from most countries of the world look to the U.S. for help and knowledge about tinnitus relief. We have had letters from a Polish professor, an Indian deaf physician, and an African tribal "witch-doctor", all asking for our help.

The United States has an opportunity to extend its preeminence in medical research and to help humanity by solving this problem which has been called the third worst thing that can befall mankind, the first two being unrelenting pain and dizziness.

Please help by funding these important programs. Thank you.

Senator HARKIN. Thank you for being here.

Dr. REICH. I wish to say we very strongly support the $165 million budget for the new NIDCD. Thank you.

Senator HARKIN. We are going to try to get that too, if we can. Carl, did you have anything that you wanted to add to this?

Mr. ROSS. No; they summed it up very well.

Senator HARKIN. Tell me about tinnitus. It happens usually later in life, I mean, younger people do not have it.

Mr. ROSS. They do. They have it from rock and roll and many children are born with it, but if they are hearing-impaired, they may not recognize it as such.

Senator HARKIN. What do we know about it in terms of— have any studies been done to see if people who live in quieter areas of the world where there is not the industrial noise and loud rock music, do people suffer from it there also?

Dr. REICH. Senator, I have had a letter from an African witch doctor which was brailled on an old piece of cardboard on a stone saying that the people in their tribes suffered from tinnitus, so obviously, it covers all parts of the world. And there are organized tinnitus associations in most major countries. The greatest cause of tinnitus is noise exposure and how ever you take your noise, either occupationally or recreationally, that can be a very great factor in it.

Mr. ROSS. In Alaska, Eskimo children who are listening to rock music at such high levels as is common now, are hearing tinnitus, they are losing their hearing and they are having difficulty hunting in the quiet because they cannot hear the soft sounds of the animals. So it is a worldwide phenomenon and it cuts across all ages.

Senator HARKIN. But no knowledge of what causes it or anything.

Mr. ROSS. The particular physiological functions are still mysterious. A lot more research will be needed.

Senator HARKIN. Now you said you wanted $165 million for the new institute we talked about earlier. But in terms of tinnitus research, do you have a figure in mind, how much?

Dr. REICH. It would take about $20 million or $30 million to get projects off the ground that would be really useful. There have been a number of studies in universities and medical schools around the country, but none of them have been large enough yet to really get to the heart of the problem. There is good groundwork, however.

Senator HARKIN. Last year, just for your information, there was $1 million spent on tinnitus research. That is not very much; $1.1 million is the request for this year.

Mr. ROSS. Well considering 30 or 40 million people have it, or even more, since so many who have it do not talk about it.

Senator HARKIN. I suppose I should talk about it. People say I should not. It has been bothering me for a long time. And like you, I went from doctor to doctor to try to find out. I went to Bethesda, I went to Walter Reed, I have been all over. I went to the University of Iowa to find out what was going on.

I still think, I suspect, I still believe that I traced mine back to 8 years of flying jets in the Navy and that very high pitched noise, even with a helmet on, that you would get from the compressor. Of course, when you are young like that, a lot of times you do it without a helmet on. You did not think about it in those days. I still trace it back to that. Now that has been some time ago, but it got worse as time went on. I found that mine varies. Sometimes it is like that, and sometimes it goes down, but you just learn to live with it and do not let it bother you. It can be distracting sometimes when you are trying to concentrate and listen to people. It can be distracting.

But I really think we need more money into the research of just what causes it. You have masking devices and things like that, but we do not know what we can do to actually cure it. I want to do a study to find out how many people that have been around high pitched sounds for a long time have had this type of affliction. The more I talk to people who did what I did in the service in terms of flying jets, and sitting up over a compressor all the time, have that affliction. They do not talk about it, they do not mention it, they just learn to live with it.

Mr. ROSS. People are made to feel embarrassed about having it and doctors, sometimes, since they do not have a cure try to push the patients away as a problem rather than being sympathetic.

Senator HARKIN. First I thought it was my hearing problem and my hearing they say is fine.

Dr. REICH. That is an indication, Senator, of how many people have it. There was a letter that I wrote to Ann Landers a few years ago. When she published it, we immediately received 120,000 letters from sufferers around the country. So it is a very prevalent problem, but we do not know the extent truly to which people are afflicted.

Senator **Harkin**. I appreciate your being here. And Tony, thank you for coming down from New York to do this today. I really appreciate it very much in helping us to focus on it. We will do our best to see what we can do to get more research money in there. We have our budget battles and if we can do what Paul Simon says, if we can get some of the money, you know I will give you one figure to take with you.

You talk about how much money, Rudy, we spend on medical research in this country. Last year, we spent about $9 billion that we put in for biomedical research, the Federal Government. That sounds like a lot of money and it is, but in the last 24 months, we have spent more on military research than we have on biomedical research since World War II. In 24 months, more on military research than on biomedical research since World War II. That is cancer, AIDS, hearing, sight, that is everything. So that kind of puts it in perspective as to what we are spending our money on.

Well, we had a hearing about that yesterday, focusing on the aspect of just how much is going into biomedical research. We are paying our researchers too little. Right now, I think, at NIH, a post doctoral researcher coming out of school, has a mountain of debts, married and maybe have a child, but they want to do research, top of the class, they are paying them about $27,000 a year. You cannot live in Washington, DC, on $27,000 a year, plus pay back college debts. Or they go out to private industry and forget about research.

Well, I did not mean to get on my soap box.

Mr. **Randall**. Thank God someone does.

Senator **Harkin**. Well, we need to get more money in biomedical research. We just need to refocus our priorities and start focusing on it. All right. Well, thank you. I really appreciate it. Thank you so much.

Mr. **Randall**. Thank you.

### STATEMENT OF HON. RUDY PERPICH, GOVERNOR OF THE STATE OF MINNESOTA

### ACCOMPANIED BY ABBEY MEYERS, EXECUTIVE DIRECTOR, NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Senator **Harkin**. Now we have Governor Perpich. Governor Perpich, it is an honor and a pleasure to have you here before the subcommittee, and to talk about—and you are with Abbey Meyers, executive director for the National Organization for Rare Disorders, Inc. And again we welcome you here.

Governor **Perpich**. Thank you. We are happy to be here and we are—thank you for the opportunity to be here this morning and before I start, of course, I am your neighbor to the north, and we know of your good work, and the people of Iowa are very, very fortunate to have you representing them in the U.S. Senate. And many of the less fortunate in the United States also, so I want to thank you.

I know I have called on you as many times as I have on my own U.S. Senators, so I thank you.

Senator **Harkin**. We used to borrow Humphrey, Mondale all the time for Iowa, so if you want, borrow me anytime. That is fine.

Governor **Perpich**. We have many times. Well, I, of course, am pleased to testify today on behalf of the fiscal year 1991 appropriation for the National Institute of Health.

A few months ago, I came to Washington and New York seeking help for my son and others like him who have an orphan disease called chronic fatigue syndrome. This illness, as you are well aware, causes recurring attacks of intense fatigue, which prevents a person from leading a normal life.

Chronic fatigue syndrome used to be called chronic Epstein Bar virus infection, and there was a small flurry of research activity where they thought that was the cause of it. And scientists have found out that Epstein virus really had nothing to do with this disease, and so what we know now is what chronic fatigue syndrome is not.

But we will never know what it is unless biomedical research is pursued in this very disabling orphan disease. So this is, I think, an important part of this whole effort, that not only would be a definition of it, but also that more work be done to see what are the causes.

When I visited the National Organization for Rare Disorders, Abbey Meyers gave me a copy of the National Commission on Orphan Disease report, which was submitted to Congress in February 1989. I was surprised there are approximately 5,000 rare orphan diseases affecting about 20 million Americans. These patients have stories that are, of course, very, very similar to my son's. No one knows what causes most of these illnesses, but they are often undiagnosed or misdiagnosed for many years.

At the National Governor's Association, Senator, I presented a resolution that was passed unanimously, and since that time, I have literally received hundreds of letters from people throughout the country that are afflicted by this condition. But as many who have—my son and many others who have this disorder, the chronic fatigue syndrome, who really get bounced from doctor to doctor, not being able to diagnose any specific disease. And then, of course, this is—ends up as hypochondriacs. So as I say, they are often undiagnosed or misdiagnosed.

In addition, 45 percent of the patients report their diseases cause extreme financial hardships on themselves and their families. This is another important point. What happens to those who really do not have the means or do not have the family support. They have real difficulties. As I say, it is a problem, even if you have that family support, and the financial wherewithal, trying to get that diagnosis, but also the efforts for the treatment. There is a number of different treatments, but no cure.

My son has immunoglobulin, but the treatment is every 3 weeks, and it costs $2,600 per treatment. And there are many others, of course, I am sure a number of people would be helped, as my son is with that, but of course, it is the dollars and the insurance, and I am sure you will be hearing much more about that also.

I guess the most shocking fact is out of $1.3 billion spent by the Federal Government in 1987, on rare disease research, over one-half was spent on rare forms of cancer. There are approximately

200 rare cancers, but there are 4,800 other rare diseases, and chronic fatigue syndrome is one of them. So I am alarmed and I guess dismayed that a scientist who wishes to study orphan disease stands a very little chance of being funded, and you are well aware of that.

I spoke to NIH officials, researchers, government personnel, and a number of others who feel that, since they do not know what causes chronic fatigue syndrome, it really is not a disease at all. So there is no comfort to know that many other orphan diseases have been, or still are, stuck in this purgatory of medicine. No one knows how to treat them, and no one is trying to find out. And I guess that is our whole effort.

I have had, as I say, many experiences. I have had a cabinet member, one of the best that I had, that was head of our pollution control agency, and head of the metropolitan council, and headed up—as Commissioner of Human Services, who was afflicted by this chronic fatigue syndrome, and went through the same steps. What is it diagnosed?

It was a very bright young woman, a lawyer, and finally it got to the point where she felt that she had to leave as Commissioner of Human Services because of the workload. And my son, the same thing: a brilliant young man, a graduate from Stanford Law School, a skier, and water-skiing and roller-skating, and very, very active, and in a way, right in the prime of life. And it is very obvious. You can tell by the color of the eyes, and the swollen glands, and the fatigue. And someone that has tried every treatment that there is. Some were even detrimental to his health. From one of the treatments he developed a kidney problem, internal bleeding, but in his effort to find a cure for this, has tried various forms of treatment.

## PREPARED STATEMENT

These people are ill. There is no doubt about that. And we have to make more of an effort to identify and give some support to the people that are afflicted. And again, my concern of those who do not have the wherewithal or the family support, they really have problems.

[The statement follows:]

# STATEMENT OF ABBEY S. MEYERS, EXECUTIVE DIRECTOR NATIONAL ORGANIZATION FOR RARE DISORDERS (NORD)

Mr. Chairman, members of the Subcommittee, the National Organization for Rare Disorders (NORD) is submitting this written testimony concerning the recommendations of the National Commission of Orphan Diseases which were submitted to Congress in 1989. The Commission was established by a 1985 amendment to the Orphan Drug Act, and it studied many issues related to research on rare "orphan diseases" for more than two years before its final report was presented to Congress in February, 1989.

Under the Orphan Drug Act of 1983, an orphan disease is defined as a rare condition or illness that affects fewer than 200,000 Americans. There are more than 5,000 of these disorders affecting approximately 20 million people in our nation today.

## Biomedical Research

The Commission found that scientific investigators believe that it is more difficult to obtain funding to study a rare disease as opposed to a prevalent disease. This means in todays restrictive fiscal environment many academic investigators are convinced that a grant application to NIH for rare disease research would be a fruitless effort. Moreover, during FY90 we have heard of dozens of rare disease researchers who have lost their funding midway through the discovery process, and we are losing both young and experienced scientists in droves to private practice and health related industries.

Though there were some on the Commission who argued for a separate NIH appropriation earmarked for rare disease research, a consensus finally developed that it would be wrong to ask you to do this. The "float the boat" theory prevailed because we felt that NIH should fund biomedical research based solely on scientific merit. The Commission felt if sufficient money would be available for RO1 grant applications, more orphan disease grants would automatically be funded, and it would not be wise to take money away from prevalent diseases to fund orphan disease research.

However, this year we have been deeply shocked by the extraordinary dive in funded RO1 grants. Just about all of the Institutes are funding less than 20% of approved grants and some are funding less than 12%. We are sensitive to the fact that Congress has not decreased NIH appropriations, so this startling turn of events has shaken the orphan disease community to its roots. For patients with orphan diseases, alleviation of pain, quality and length of life, relies solely on advancements in biomedical research. Without NIH grants there is virtually no hope that any advancements will ever occur.

We cannot help but wonder why Congress has earmarked so much money for small business grants, AIDS research and the Human Genome Project without considering that in the absence of new money supplemented to the budget for these high priority initiatives, the money for "set asides" has to be taken from other diseases. Since orphan disease research is apparently not a high priority (unless you happen to have one of these devastating illnesses), rare disease grant applications do not stand a fair chance to compete for funding in today's fiscal environment.

The Commission found that in 1987 $1.3 billion was spent by the federal government on rare disease research, but over half of this sum was spent on approximately 200 rare forms of cancer, leaving only $640 million for the remaining 4,800 known orphan diseases. Obviously, funding for rare disease research is inadequate, and this year (FY 90), it is disastrous.

## Clinical Research Centers

During the 1980's, NIH drastically reduced funding for Clinical Research Centers (CRCs). No other research resource addresses the needs of rare disease patients and investigators as directly as CRC's. We ask this committee to increase the funding for CRC's by $40 million over the next four years so that additional beds can be added and new CRC's opened in an effort to treat patients who have no place to turn for expertise in their orphan disease.

## Epidemiology

Epidemiological studies on orphan diseases are sorely needed in order to determine the incidence, prevalence and transmission of rare disorders. For too many of these understudied illnesses, the cause remains a mystery. We owe it to families with rare diseases to at least understand whether their condition may have a genetic, viral, environmental or other basis of transmission.

## Coordination

The Commission also found that many of the barriers to progress in orphan diseases is caused not only by the lack of funding, but by a lack of coordination between existing resources. One area of the government research establishment doesn't know what the other is doing, and they don't coordinate their work with the FDA, health related industries or non-profit foundations. Thus valuable resources are wasted.

Perhaps the most important recommendation of the Commission was that a **central office for rare diseases** should be established to coordinate research activities on rare diseases, promote and monitor implementation of the Commission's recommendations, subsume the current responsibilities of the interdepartmental Orphan Products Board, and report to Congress yearly on federal activities related to orphan diseases. Congressional language to establish this central office within the Assistant Secretary for Health's Office is sorely needed to avoid further duplication of effort and promote wise use of existing resources.

## Information Dissemination

Finally, the Commission found that dissemination of current and accurate information about orphan diseases should be a very high priority of NIH. Due to funding cutbacks and ridiculous approval procedures fraught with red tape and departmental clearances, many disease-specific pamphlets developed by NIH for distribution are outdated and often inaccurate. For example, if you write to NIH about one of the following diseases, you will receive a pamphlet that has not been updated since the listed year:

| Disease | Year of Publication |
|---|---|
| Neurofibromatosis | 1983 |
| Lipid Storage Diseases | 1984 |
| Tourette Syndrome | 1983 |
| Torsion Dystonia | 1982 |
| Huntington's Disease | 1979 |
| Spina Bifida | 1976 |
| Cerebral Palsy | 1980 |
| ALS (Lou Gehrig's Disease) | 1977 |
| Epilepsy | 1981 |
| Friedreich's Ataxia | 1982 |
| Aphasia | 1979 |
| Acoustic Neuroma | 1973 |
| Brain Tumors | 1981 |

Interestingly, the National Cancer Institute (NCI) recognized this problem long ago and 1974 amendments to the National Cancer Act exempted NCI from departmental clearance of publications about the cause, prevention, diagnosis and treatment of cancer. We feel very strongly that all of the Institutes should receive an exemption from departmental clearance procedures for educational materials about all diseases, both rare and prevalent. The absence of current and accurate information about any health problem simply leads to greater health care costs in the long run.

## FY91 Appropriations

Many people feel that NIH's FY90 budget is about $1 billion less than the amount that is needed to maintain the thrust of advancements in biomedical science that characterized the last decade. For example, an

August 4, 1989 editorial in the journal Science commented that the new orphan drug Eldepryl (deprenyl), which significantly slows the progression of Parkinson's disease, will save the U.S. $10 million for every week that Parkinson's patients can remain functional enough to continue working. The money will be saved in the balance of taxes and disability payments that would have been paid to patients who could no longer work because of Parkinson's symptoms.

The discovery that Eldepryl could significantly slow the progression of Parkinson's in newly diagnosed patients with the disease was made in a clinical study of 800 patients by NINDS, called the DATATOP study. Can our nation afford to cut back on NIH's extramural research grants in light of this one example? Similarly, it costs $50,000 per year for every child who must undergo dialysis, and $20,000 per year for every adult. Can we afford to abandon investigations into controlling the underlying diseases that cause kidney failure so that someday there will be no need for dialysis treatment? The cost of only one RO1 grant is the same as treating 2 pediatric dialysis patients for a year, and far less that the cost of one kidney transplant.

Moreover, many older established investigators don't know as much about molecular biology as the younger investigators trying to enter the field of research. There is little chance that young scientists can obtain funding from NIH in todays fiscal environment and it is likely that we will lose the unfulfilled promise of their intellect forever.

We ask this subcommittee to take a closer look at the way NIH is spending its appropriations and whether it is fair to continue earmarking funds for specific diseases and "Manhattan Projects" if money needed to support such programs is to be taken out of other diseases? Indeed, we submit to you that there should be no "high priority" or "low priority" diseases. The politicization of NIH has gone too far! The scientific quality of research proposals is all that should matter, and mediocre proposals should not be funded simply because a certain amount of dollars are required to be spent on a specific disease.

Moreover, we question why our nation is in an apparent race to be the first to identify the human genome when researchers who have identified chromosome markers for a specific disease have lost their funding to pursue a disease gene? Can the American taxpayer afford $58.5 million this year for the genome project while other countries are duplicating the same research? All of mankind will be the beneficiaries and no nation will "own" any of the genes they identify. We also ask you to determine how much of NIH's funds had to be diverted this year for conformance to new animal welfare regulations as well as extra security to guard against the terrorism of animal rights groups who are destroying research facilities and intimidating scientists. Finally, we ask you to look again at indirect costs which have skyrocketed out of control, in some instances doubling the cost of RO1 grants.

We know that many of the witnesses who appear before you will ask you to raise the priority of their disease or program. We are asking you instead to return the NIH to the premier research institution it once was, to remove politics from funding decisions, and permit NIH to fund at least one-third of approved RO1 grant applications as it did in the beginning of the last decade. Your appropriations should not be earmarked for any disease, and projects involving groups of related diseases should be encouraged. Grant proposals should compete for funding and only the best science should be funded. This is the only way we can attract and retain investigators into orphan disease research.

Thank you.

Senator HARKIN. Thank you. You are the first one that brought this to my attention last year. I had not known about this rare disease before, and you were kind enough to come in and enlighten me on it, and again, to be here today. It is something that we need some more research on. Evidently they just have not spent the money or done the research on it that needs to be done.

Governor PERPICH. No one knows how to treat it, but no one will ever know these answers unless NIH is required to aggressively track and fund researchers for chronic fatigue syndrome. It is much like Alzheimer's. You know, 10 years ago, they thought it was a matter of getting old and senile. Now, of course, they know that is not true. I think the same was true with multiple sclerosis [MS] at one time. They believe this is in the family of poliomyelitis, multiple sclerosis, lupus, but this is in the same family, and there are areas that were hit hard.

My son, when he was at Stanford, was in Nevada at the point where this is one of those clusters, Lake Tahoe—about 300 or 400 that they diagnosed coming from that one area. They had the same thing in other parts of the United States, where you have clusters of people that were in that area at that particular time, so no one knows. Is it the environment? Is it from a virus? But we have to make more of an effort to identify it.

Senator HARKIN. What we did last year. About $3 million, about $3.03 million last year in the National Institute for Allergy and Infectious Diseases, and then in the Centers for Disease Control split about half. Their request this year is for the same.

In the report language for fiscal year 1990, this committee suggested that the National Institute for Allergy and Infectious Diseases establish a research center for chronic fatigue syndrome studies to collect and analyze clinical and laboratory data on patients. NIAD funded three small grants, but has not funded a research center yet. Again, we will be asking them about that, and see whether or not we can get that center.

Ms. MEYERS. Would it be possible to have NIAD issue a request for proposals or request for a contract to make sure that that center does get funded?

Senator HARKIN. We will certainly ask that. We will certainly try to get that information from them as to why it has not taken place as of yet.

Ms. MEYERS. So out of the $3.5 million you appropriated last year, it has not been spent?

Senator HARKIN. No.

Governor PERPICH. That is a big part of the problem.

Senator HARKIN. That is a part of the problem. Abbey Meyers, did you have anything else to say? You were covering a broader base than this.

Ms. MEYERS. Yes, I am, on 5,000 different diseases. I testified yesterday at your oversight hearing and was very pleased to have the opportunity to do that. We simply want to ask you to look at the report of the National Commission on Orphan Diseases, which was submitted to Congress last year, and to understand the impact that NIH has on these little known diseases.

It just seems that biomedical research many times gets funded according to the degree of the public's fear. Since nobody fears they are going to get chronic fatigue or they are going to have a baby with Tay-Sachs disease, et cetera. These diseases are languishing and in some of them, no physician in the world is studying them at all. This is what we have to do. This is one disease that it just illustrates all the problems with orphan diseases.

Senator **Harkin**. I am not a scientist. I do not pretend to be one. But I have spent a lot of time on science and technology, both in the house committee and over here. Again, it is a matter of priorities and where we put our money. We are being asked to spend up to several billion dollars to build an atom smasher in Texas, to find out what happened in the first milliseconds before the big bang or right after the big bang. I am not opposed to that. Scientific inquiry is good.

But we have another parallel thing that we are working on now that is a big science project. It is called the study of the human genome. That is going to cost about $7 billion too.

Ms. **Meyers**. We are disturbed about that, Senator, because we know many, many scientists who have been funded for genetic research on specific diseases, that have collected the tissue, the blood samples, et cetera, and they have lost their funding this year. If the plug has to be pulled on those refrigerators, and those blood samples have to be thrown out, it will set genetic research back 10 years, so we do not understand why this Manhattan Project is being funded for the human genome project. The money is being taken away from the scientists who are actually studying specific genetic diseases.

Senator **Harkin**. My point is I happen to be a big proponent of the human genome project. And the more that we can put into the human genome project, the more we do not have to do the kinds of things you are talking about. But the sooner that we map the human gene, and I believe it can be done within the next 10 years, the better we will be able to answer some of these very fundamental questions about what is happening on these rare diseases. And what the genetic traces are of many of those.

I just feel very strongly while it might be nice to know what happened in the few milliseconds after the big bang, knowing, mapping, and the human gene and sequencing the human gene has much more, I think, application to our health and well-being then knowing what happened in a few milliseconds after the big bang. I was just using that as an example. Now you are talking about a different side of that and that is those individual researchers that are out there doing genetic research, and those can be folded right into the whole human genome project, they are not getting funded.

Ms. **Meyers**. They have lost their funding. In one case we know of a fatal kidney disease that kills children before the age of 10. There were two scientists in the country studying that disease, and they both lost their funding. So what I would ask you to do is please fund the human genome project, but do so out of extra funding. Do not take it from the slice out of the pie that exists.

Senator **Harkin**. Now we are singing the same song. I am saying you do not rob Peter to pay Paul, and biomedical research. All right, thank you very much.

### STATEMENT OF MARGARET STOUT, EXECUTIVE DIRECTOR, IOWA ALLIANCE FOR THE MENTALLY ILL

### ACCOMPANIED BY LAURIE FLYNN, NATIONAL ALLIANCE DIRECTOR

Senator HARKIN. Margaret Stout, executive director of the Iowa Alliance for the Mentally Ill.

Welcome. This morning your statements will be made a part of the record. I am going to ask everyone that is testifying this morning, instead of reading any testimony, what are the two or three things that you want me to know about that I will write down here and remember?

Ms. STOUT. Thank you, Senator. Mr. Chairman, I am pleased to be here today, particularly to testify before a fellow Iowan, and as Laurie mentioned, Laurie Flynn is our National Alliance Director who I have sitting with me to also help give you a couple more things to remember.

I guess I would like to have you remember, Senator, that 10 percent of all Americans suffer from a serious mental illness, and 20 percent will be afflicted at some time with an episode. I think that is an important thing to keep in mind. Lots of those folks are also suffering from a dual diagnosis problem. I know you are very interested in substance abuse. I want you to remember that many of the folks with mental illness also have the dual problem and vice versa.

We would like to have you remember that we need an increase in research. We have requested $193 million. I know that sounds enormous, as an increase, but our disease has been underfunded for so long, and I think that is why you are now seeing those of us who have had family members who have suffered for many, many years are coming out and talking about the disease, which obviously, with the increase that we requested, it exhibits that as to why.

I want you to look at and support NIMH and our research request to do more in studying why people who have an economic crisis sometimes will suffer from more depression, which particularly affects Iowans. We have recently lost five young men in Dubuque County, Iowa, which I am sure you are very familiar with the Dubuque area. All of them to suicide. I understand there were two individuals who suffered from a dual diagnosis problem, and the other three apparently suffered from depression.

Senator HARKIN. That is interesting that you just mentioned this because we have not talked about this before. A couple of weeks ago, I was driving outside of Dubuque—an individual was driving me—I will not mention her name, told me that she wanted me to look into something. I said, what's that, and she said in her area, and she defined it basically as her township, I think since the first of the year, four farmers had committed suicide.

Ms. STOUT. That is probably what we are talking about.

Senator HARKIN. And you said five, in and around Dubuque.

Ms. STOUT. And I have heard that there could be another individual also involved in this, but I could not check my data before I came out here. So there is something wrong. You know, the farm crisis is not over in Iowa. We think it is, but it is not.

Senator HARKIN. I mentioned that the other day, and someone from Kansas said it was happening in Kansas. They have had farmers still committing suicide, too. I said to this woman, now how come I did not read that in the paper? I read the paper. How come I did not read that? She said something very interesting. I have got to look into this. She said, a lot of times the papers are not reporting it. Now the sheriff's office investigated, knows it was a suicide, but the newspaper just printed the person had died.

Ms. STOUT. I think it is the stigma. I am not sure that family members are willing to come out and indicate that someone has been suffering from depression for a long time, and did not access the system.

### PREPARED STATEMENT

Another thing I would like you to remember is the shortage of psychiatrists that we have in Iowa, and the location of those psychiatrists. We do not have them available to everyone, particularly if you are living in a rural area.

Senator HARKIN. I am sure that is true for rural areas all over America.

Ms. STOUT. Access to care is an issue. I could go on and on here, but you asked me to wrap it up.

[The statement follows:]

## STATEMENT OF MARGARET STOUT, EXECUTIVE DIRECTOR OF THE IOWA ALLIANCE FOR THE MENTALLY ILL

"We must also expand our research efforts if we are to learn more about how to prevent and treat the crippling or malfunction of the mind." Mr. Chairman, those words were contained in the Message from President John F. Kennedy to the Congress on February 5, 1963. He emphasized in that Message, "Although we embark on a major national action program for mental health, there is still much more we need to know. We must not relax our effort to push back the frontiers of knowledge in basic and applied research into the mental processes, in therapy, and in other phases of research with a bearing upon mental illness."

Even in these enlightened times, it is clear that mental illness, though a problem of major proportions which adversely affects our health, well-being, and productivity as a Nation, is still shrouded in mystery, shame, and stigma. Notwithstanding President Kennedy's challenge over a quarter of a century ago, the unfair and unreasonable attitudes associated with illnesses of the mind and brain still carry over into our public policies so that the mental health field has been chronically and severely under-funded. Mr. Chairman, the proposed budget for fiscal year 1991 does not indicate any change in this situation. Therefore, I am here today to advocate for more research funding for the National Institute of Mental Health (NIMH).

I also will share with you some of the pertinent activities which are happening in Iowa as an example of what is going on in the states which include our 935 affiliates. I am representing 7,500 Iowa Alliance for the Mentally Ill (AMI) members as well as the 80,000 members of the National Alliance for the Mentally Ill (NAMI). All of us in AMI, lay, and professional, have family members with mental illness or have had mental illness ourselves. Iowa has support groups around the state to provide the needed support to one another. We advocate for more research, legislation, and provide public education about serious mental illness.

The AMI of Iowa is very proud that we will soon be a part of the NIMH's D/ART (Awareness, Recognition, and Treatment) program. We will be launching an Iowa program to alert the public, primary care physicians, and others about depressive disorders -- their symptoms, diagnosis, and treatments. We want to convey the message to everyone in Iowa that depressive disorders are among the most responsive to medical treatments.

Depression will affect 10 million people within the next six months; their families, friends, work and their social life. The cost of this disease is constantly under fire by employers who must pay for insurance benefits. Loss of insurance or inadequate coverage for mental illness is also a burden to the person with the illness. We are hoping that our awareness program on depression will provide the person with knowledge about depression and early access to the treatment system.

The NAMI held an innovative symposium at Grinnell College in Grinnell, IA about depression. This symposium was one of two held in the nation on a college campus. The purpose was to alert college students to the symptoms and available treatment for depression. Counselors reported an increase in students seeking help following the symposium. This year teleconferencing was used to reach college campuses around the nation. Iowa had many colleges participating in this program.

During the last six weeks depression and substance abuse contributed to the loss of five young men in Dubuque County, IA. All five of these men committed suicide. We can only surmise that treatment was not sought out because of stigma and lack of knowledge about help being available.

It is known that two of these individuals suffered from substance abuse and mental illness which precipitated in their tragic deaths. Three men were having economic and farm crisis related difficulties. Therapy and medication could have saved these young men's lives if they only had accessed the mental health delivery system. We must get the message out that depression and substance abuse are treatable diseases -- we do not need to suffer -- mental illnesses are no different than any other disease.

Because Iowa is basically rural, it may take longer to convey our message throughout the state. Another difficulty for Iowa is the lack of psychiatrists within the state. Data from 1988 indicates there were 219 psychiatrists in our state which means there is one psychiatrist available for every 12,900 Iowans.

Iowa's population in 1987 was estimated to be 2,834,000. The recommended service definition ratio from the U.S. Public Health Service for psychiatrist to patient is one psychiatrist to 30,000 persons. These statistics are distorted by our rural nature because the general population and the psychiatrists are not distributed equally throughout the state. The maps in the appendix show the overall shortage and the location where the majority of psychiatrists are located in two counties, Johnson and Polk. The remainder, or 123, then must serve the balance of 97 counties in Iowa. Depression sufferers residing in Polk and Johnson counties therefore have a much greater chance of getting appropriate treatment.

Iowa's problems are much like those of other rural states and areas in the Nation. Our residents with chronic mental illness do not have the needed options to maximize their potential as individuals and to live a life with dignity and respect. To be specific, I now list ten services critically needed now in Iowa:

* Equal parity for mental illness coverage on insurance policies;
* Crisis beds as an alternative to hospitalization;
* Vocational and job opportunities (psycho-social services);
* Low cost housing;
* Outpatient mental health care;
* Case management services;
* Transportation;
* Consumer-run alternatives;
* STIGMA reduction;
* Caring mental illness professionals.

I will not belabor these points because I know you are acutely aware, Mr. Chairman, as am I, that this section of the President's Budget proposal is not acceptable to rural Americans, whose unique problems constitute long-term social and economic changes that are contributing to the decline in the quality of life in rural America at enormous human cost. The increasing mental health needs of rural Americans emanate in part from the devastating and abrupt end of general agricultural prosperity in this country, and are manifested in a depression rate among adolescents that is twice the national average, increased rates of child and spouse abuse, a doubling of the rate of depression among adults in many rural areas, and an increase in mental illness among our homeless population.

Now looking at the total national scene, consider, for example, that more than 40 million U.S. adults are afflicted annually by such mental disorders as schizophrenia, depression, manic depressive illness, Alzheimer's disease and anxiety disorders. Even more disheartening is the knowledge that among children and adolescents, probably 7.5 million -- or 12 percent -- under age 18 suffer from one or more mental disorders. The economic costs of mental illness are also staggering -- the direct costs are estimated to exceed $40 billion each year, and the expected indirect costs exceed $50 billion. In addition, $50 billion in productivity is lost annually.

By any statistical measure, then, mental illness is one of the most widespread, destructive, and costly public health problems in the United States today. But even this cannot convey the human toll of mental illness, both for the direct victims and for their families. Chronic mental illness can, and often does, devastate the emotional, social and financial lives of patients and those closest to them. Mentally ill Americans and their families must cope daily with severely disrupted lives, misunderstanding, stigma, and the fact that only one-fifth of people identified as having a mental illness are actually under treatment.

As a result, 10 years ago, a grassroots, self-help support and advocacy organization of people with serious mental illness and their families and friends created NAMI. I am pleased to point out that our mission is to eradicate mental illness and to improve the quality of life for those who suffer from these no-fault brain diseases. As I mentioned, in 10 years we have become an active and growing organization with 935 affiliates nationwide and approximately 80,000 members.

NAMI continues to fight to maintain a logical scientific and cost/benefit balance in research funding. It is unfortunate but this is a result of the fact that Congress has an unhealthy tradition of inequitable support for basic biomedical research on other physiological diseases affecting man. Funding support for diseases like cancer, heart and lung diseases far eclipses that spent for the major mental illness of schizophrenia, despite a prevalence that suggest that it is absolutely imperative to fund more research on diseases of the brain.

Moreover, unlike other health issues, mental illness has no significant private sector constituency committed to research, so that progress is dependent upon the responsiveness of this Subcommittee and the Congress as a whole. The National Institute of Mental Health (NIMH) is the largest scientific institute in the world with a primary focus on mental disorders. In addition to approximately 600 investigators in its intramural research programs, NIMH provides approximately 90 percent of all other research efforts on mental illness in America. In order to continue its efforts in a manner commensurate with the magnitude of the challenge, the NIMH must receive support far above that envisioned in the FY 1991 President's Budget.

Moreover, the President's Budget jeopardizes the great momentum which a steady support of research has built into real gains in scientific knowledge about the biological basis for many of the major mental illnesses. Through continued basic and clinical neuroscience research, we are increasingly able to understand the normal functioning of the human brain, and are thus closer to understanding, and even anticipating, its dysfunction. This kind of knowledge, in turn, will offer the real hope of achieving the ability to intervene in the disease process to prevent its occurrence. Underlying the success of much of the basic and clinical research that has virtually revolutionized neuroscience are amazing new technologies enabling scientists -- through imaging tools such as positron emission tomography (PET), magnetic resonance imaging (MRI), brain electrical activity mapping (BEAM), and computerized tomography (CT) -- to uncover the intricate pathways through which the brain's messages flow, and literally watch as the brain functions. These technologies are expensive, however, and their continued development and support depends on funding above that proposed by the Administration.

It is clear that the President's Budget will significantly constrain ongoing research activities and ignore the need for expanded research and increased funds for research training. For example, the NIMH initiatives called for under the National Plan for Schizophrenia and Brain Research and the newly-issued National Plan for Research on Child and Adolescent Disorders will not be fully developed to take optimum advantage of recent advances in the mental health field.

Less than full support for this research is just not acceptable to the NAMI families, especially to the mental health of the nation as a whole. Nor is it acceptable to the individual men, women, and -- most urgently -- the children, directly affected by mental disorders. Take, for example, some of the young lives full of pain described in the National Plan on Children and Adolescents. The President's Budget level is not acceptable for people like Bridget, a bright, witty, and talented crown jewel in her bleak, inner-city neighborhood who, at the age of 16 suddenly showed up in a hospital emergency room after cutting her wrists; nor is it acceptable to John, a 5 year old who does not speak very much or very well, cannot get along with other children and whose mother descries him as "living in a shell" -- finally diagnosed as being autistic; nor is the President's Budget acceptable to Robbie who has been a difficult child since he was an active and stubborn toddler and whose beleaguered parents want him out of their home at the age of 13.

However, the President did sign legislation declaring the 1990s as the "Decade of the Brain". He signed this in recognition of the unique accomplishments and potential in the field of neuroscience, but now we note the lack of support in his Budget for those with serious mental illness. This is very disappointing because there is great hope that basic research findings and clinical advances in the very near future might provide relief to countless victims of mental disorders doomed to living in their own private hell until then. In addition, the progress already achieved will be greatly slowed if we fail to provide the proper environment and support for research and the training of future leaders in biomedical research. Mr. Chairman, we simply must adequately support the scientific promise and progress the President's signature on the Decade of the Brain Resolution celebrates.

## PAST ACCOMPLISHMENTS

Mr. Chairman, your past generous support for biomedical research in the neuroscience areas is now beginning to pay off, and pay of handsomely. Thanks to this unwavering support, millions of patients are now leading more productive, less painful lives. Drugs have been developed which have saved billions of dollars for the Nation's economy and , for victims of major mental illnesses, have replaced hopelessness with hope, and made it possible for them to live and work in the community free of unbearable suffering. Lithium carbonate, for example, has freed victims of manic depressive illness to live free of their wrenching, wildly exaggerated emotional highs and lows.

Mr. Chairman, there now truly exists the research capability to reap incomparable benefits for patients with many other mental disorders. There is, for example, a new drug on the horizon which offers unprecedented hope to previously treatment-resistent victims of disabling schizophrenia. These patients have been found to improve significantly when treated with this drug, clozapine. Recently, researchers have identified a class of drugs effective in the treatment of obsessive-compulsive disorders, which locks its victims into uncontrollable and inappropriate behavior. The brain imaging techniques I mentioned earlier can actually identify structural and functional brain abnormalities in schizophrenia, abnormalities which recent finds suggest may arise early in development and precede the onset of brain disease. These same techniques have shown that there is abnormal activity in the brains of dyslexic adults while they perform a cognitive task and have shown that the hippocampal region is markedly reduced in size in the brains of memory-impaired patients. Researchers are now using molecular genetic technology to examine the origins, diagnosis, treatment, and prevention of severe mental illnesses. Research has also shown that depression is not confined to adults, but affects children of all groups as well, and has provided evidence that genetic factors may play a role in vulnerability to mental disorders of childhood and adolescence.

## ALTERNATIVE BUDGET PROPOSED

Mr. Chairman, every organization in the Mental Health Liaison Group (MHLG) is aware of the remarkable opportunities to make quantum leaps in progress based on existing neuroscientific knowledge and rapidly advancing technology. In order to take full advantage of these opportunities, the AMI of Iowa and NAMI are recommending a total FY 1991 budget of $750 million for NIMH. This includes $675 million for research -- which includes AIDS research, research training, and research management and support -- an increase of $193 million above the President's Budget proposal. Of our total recommended figure, $575 million is needed for non-AIDS research on many of the promising NIMH blueprints critical for the next decade including the National Plan for Research on Schizophrenia, the National Plan for Research on Child and Adolescent Mental Disorders, the Report on the Decade of the Brain, and the National Research Strategy to Improve the Care of Patients with Long-Term Severe Mental Illness. Mr. Chairman, as these plans testify, the NIMH is well

**prepared and poised to fully utilize this budget we are proposing. In fact, they are essential if we are to meet our goal of conquering mental illness by the year 2000. Further, the fields of basic neuroscience and behavioral science are ripe with genuine opportunity; inadequate support will only doom the mentally ill to additional years of suffering and pain.**

**Mr. Chairman, I am sure we all will agree that there are many line items in the budget, impacting on serious mental illness, worthy of detailed discussion. However, in regard to the Subcommittee's need for concise expression, yet as a special service to this Subcommittee, I respectfully request that the detailed ALTERNATIVE BUDGET, just endorsed and released this week by the MHLG made up of 60 organizations, of which NAMI is a member, be included at the conclusion of my remarks.**

**OPPORTUNITIES**

Mr. Chairman, I just want to take a moment to briefly highlight those opportunities -- what NIMH will do immediately with the additional funding. But also, in anticipation of what you and the members of the Subcommittee will ask, I will also list what opportunities will be lost or greatly delayed -- what NIMH can but will not be able to accomplish without the budget NAMI is proposing. In this regard, the words of a famous coach sum up our philosophy -- "The future is now."

**Research Project Grants**. NIMH will be able to award 625 new and competing research project grants in FY 1991. This is 347 more than the number of grants which could be supported in the President's Budget;

**Research Training Program**. In this activity, Mr. Chairman, it is absolutely critical that NIMH be given resources to expand the research training program to prepare talented young scientists for careers in the mental health field;

**Full Implementation of the National Plan for Research on Child and Adolescent Disorders**. As you all probably know, the Congressional Wives have formed an interest group which is currently sponsoring a series of seminars on the Hill emphasizing that children with severe mental and emotional disorders have been too long neglected. The NIMH Plan aims to correct that -- we must support more research into the underlying causes of the mental disorders of childhood. Recently the NIMH commissioned a study by the Institute of Medicine (IOM) to prepare a report describing research needs in this area. The IOM found that almost every area of research warranted significant expansion -- the National Plan is the response -- it must be supported with adequate funds;

**National Research Strategy to Improve the Care of Patients with Long-Term Severe Mental Illness**. At a minimum, 2-1/2 million Americans suffer from long-lasting mental or emotional disorders that seriously interfere with their ordinary daily functioning. One of the greatest challenges facing America's mental health system is to provide appropriate care and services to this special group of very vulnerable and helpless patients who have long-lasting and persistent mental illness. This Plan would bolster efforts to advance the science underlying the improved diagnosis, treatment, and services relevant to individuals with severe mental disorders by stimulating expanded clinical services research, service systems research and other activities to provide appropriate care and services;

**National Plan for Research on Schizophrenia**. Full funding of this Plan would assure expanded MRI studies on schizophrenia to determine subtle signs of reduced brain volume in afflicted individuals, and quick, full evaluation of clozapine, an amazing new antipsychotic drug found to be effective in schizophrenics previously resistant to treatment;

**Functional Brain Imaging Centers for the Study of Mental Disorders**. The budget proposed today would increase the national base of functional brain imaging facilities which are specifically dedicated to research on mental disorders -- a major initiative to stimulate and facilitate the use of advanced physical brain imaging technique in the study of mental disorders;

**Psychotherapeutic Medication Development**. This budget could support a program to develop new and novel medications for the treatment of mental disorders, including experimental approaches involving molecular modeling techniques as well as controlled clinical testing of compounds that are developed.

Mr. Chairman, these Plans are all in place, ready to be completed if so directed by this Subcommittee and the Congress. Now I will briefly list those opportunities which are also critical, but may be lost without the initial and decisive action of this Subcommittee:

* additional linkage studies to identify genes that underlie such severe mental disorders as schizophrenia, manic-depressive disorder, and Alzheimer's disease;

* a multi-center collaborative treatment trial for attention deficit/hyperactivity disorder (ADHD) to clarify the various causes of this illness;

* a multi-site longitudinal study on child and adolescent mental disorders;

* establishment of a center for research on psychological and combined therapy and medication treatments of child and adolescent mental disorders;

* further studies of quinolinic acid, a potential neurotoxin, in the cerebrospinal fluid of patients with AIDS dementia;

* develop new strategies to identify the chromosomal locations for genes that may predispose individuals to manic-depressive illness, schizophrenia, Alzheimer's disease, and other neuropsychiatric disorders;

* further investigate the causes and natural history of AIDS dementia in HIV-infected children, and the effects of the HIV virus on the developing nervous system;

* fund services research and research demonstration grants on homelessness and its relationship to mental illness.

SERVICES

Mr. Chairman, research has shown that persons who suffer with serious mental illnesses such as schizophrenia, manic-depressive illness, and major depression can benefit significantly from community-based habilitative and rehabilitative services. However, states and localities have faced significant problems in delivering these services in a comprehensive and coordinated fashion to individuals who require them. In this regard, I feel it is most important to call the Subcommittee's attention to three programs.

ADM Block Grant. The Alcohol, Drug Abuse and Mental Health (ADM) Block Grant is a major source of funding of community-based mental health services. NAMI joins other members of the MHLG in urging that $3 billion be appropriated for this grant in FY '91. We emphasize the important role of your Subcommittee in targeting persons with serious mental illnesses as a priority population to be served with monies from this block grant.

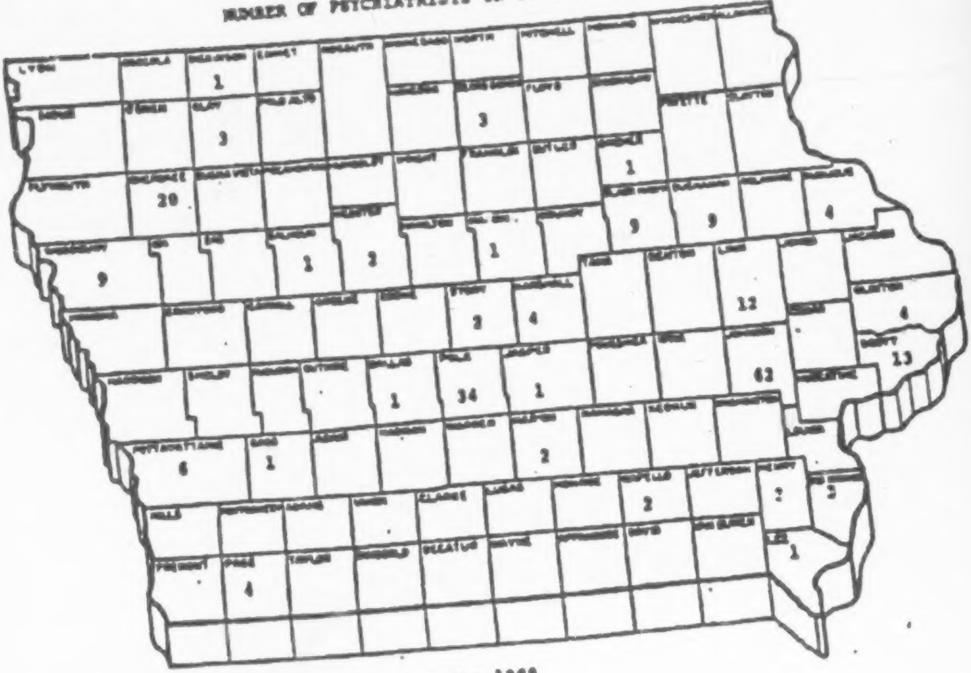
State Mental Health Planning Grants. The "State Comprehensive Mental Health Services Plan Act of 1986" (PL 99-660) requires states to develop annual plans for implementing comprehensive and coordinated community-based services for persons with serious mental illnesses. Recognizing the importance of family and consumer participation in the development of these plans, your committee appropriated $4.5 million to be distributed to states to engage in comprehensive planning and monitoring activities. These monies were used to incorporate families and consumers into the planning process. They also enabled the NIMH to provide important technical assistance to states in developing their plans. An unfortunate consequence of the complex budget process is that good programs sometimes fail to be renewed. Many of our members in Iowa and around the Nation report that their states have significantly cut back on family and consumer participation in developing plans for FY '90 due to the absence of funds for this purpose. We therefore urge your Subcommittee to appropriate a similar amount for FY '91. This appropriation will significantly enhance the ability of states to continue with vitally important comprehensive planning activities.

**McKinney Services Block Grant for Homeless Individuals with Serious Mental Illnesses**. This important program authorizes formula grants to be administered to states to provide mental health services to individuals who are homeless and seriously mentally ill. To receive the grant, states are required to provide outreach, community mental health services, rehabilitative services, case management, and supportive services in residential settings. Funding of this program has been uneven and has resulted in some states in lack of continuity of services for this vulnerable and highly needy population. NAMI joins with the MHLG in recommending that $100 million be appropriated for this program in FY 1991.

Mr. Chairman, it's been an honor and a privilege to appear before you and your distinguished colleagues today. Therefore, I have listed these very concrete and real projects whose sole goals are the goals of NAMI -- to ease or end the suffering of those who are victims of a terrible disease. Except for those who are suicidal or afflicted with AIDS dementia, mental diseases are not usually fatal in the common sense of the word. You can be sure, however, that mental illness ends productive, fulfilling and satisfactory life for many, many of its victims. If the scientific opportunities just described are not seized, millions of American citizens now and in the future will be doomed to needless pain and unfilled potential. Mr. Chairman, I ask you and all the Subcommittee members to consider this as you deliberate on the vast Labor-HHS-Education-Related Agencies Appropriations bill for FY 1991. I also ask the Subcommittee to consider, Mr. Chairman, that our Nation will bear an enormous and unnecessary burden of social and economic cost if the mentally ill continue to be neglected. Neither America nor its people can afford to pay such a price.

# APPENDIX

## NUMBER OF PSYCHIATRISTS IN IOWA BY COUNTY

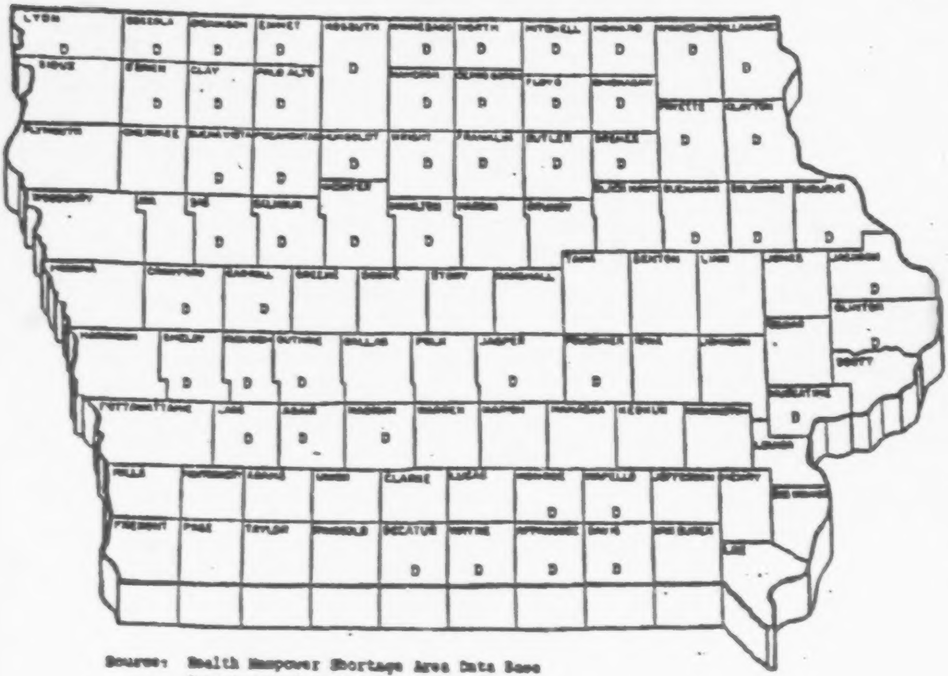


**Source:** Iowa Medical Society, November 1988
Total 219 Psychiatrists

Note: Psychiatrist distribution
Cherokee Co. - Cherokee MHI
Woodbury Co. - Sioux City
Pottawattamie Co. - Council Bluffs & Omaha, Ne.
Polk Co. - Des Moines
Johnson Co. - Univ. of Iowa & contracts with Mt. Pleasant MHI
Linn Co. - Cedar Rapids & Waterloo.
Scott Co. - Davenport & Moline, Ill.

The following map shows the counties that have been designated by the National Public Health Service as psychiatric health manpower shortage areas.

Designated as Psychiatric Shortage Areas
(As of 1/7/87 and update for 1 Area 12/88)



Source: Health Manpower Shortage Area Data Base
Department of Health and Human Services

## OVERVIEW

This document presents a consensus of the views of a coalition of consumer, provider, professional, and citizen advocacy organizations.

We believe the federal government must much more seriously assess the national impact of mental illness, alcoholism, and drug abuse, the economic consequences of which are comparable to such physical disorders as heart disease and cancer, and must respond accordingly with public funding commensurate to these national problems. Within a six-month period more than 19 percent of the U.S. population suffers a diagnosable mental disorder or an alcohol or other substance abuse disorder.

There is no satisfactory reason for the Administration to continue to propose budgets that fail to reflect the grave national burden of mental disorders, alcoholism and drug abuse. The compelling findings of a 1984 Institute of Medicine Study ("Research on Mental Illness and Addictive Disorders: Progress and Prospects") remind us that these disorders directly afflict 30 to 45 million people and cost $68 billion annually in direct health care costs with total economic costs of $250 billion.

The IOM study, along with the 1988 "National Plan for Research on Schizophrenia and the Brain", and the new "National Plan for Research on Child and Adolescent Mental Disorders" reveal that the nation has an historic opportunity to find the causes of, and develop treatments for, these disorders in order to better control them and ultimately prevent them. Small advances through research will result in enormous direct and indirect savings to the federal government and society.

The President's FY 1991 budget reflects an alarming lack of concern. We are reminded by the IOM study that since 1966 "the real level of federal support has dropped markedly." Our budget recommendations reflect an urgent national need to "catch-up" in the funding of mental health, and alcohol and drug abuse programs after two decades of a decline in the buying power of ADM funds.

For the research programs of NIMH, NIDA, and NIAAA, the President's request falls short of "current services" levels. This is despite the fact that ADAMHA supports more than 90 percent of the Nation's biomedical and behavioral research on alcohol, drug abuse and mental illness, a proportion of total support which is roughly double that contributed by its sister agency, NIH, to general health research. Research training — an integral part of the research agenda of the ADAMHA Institutes — is continued at less than current services levels. Vital planning, protection and advocacy and clinical training programs are greatly reduced, despite no decline in need. National shortages of mental health professionals have not been alleviated. Program support levels have again reached dangerously low levels. The fiscal committment to the "War on Drugs" falls well short of the rhetoric.

Our recommendations for funding for the programs of the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA) rest on a professional assessment of need and expenditure of funds. They address the multi-faceted components of the ADAMHA mission, which is to provide national leadership responsive to the public health problems of mental and addictive disorders.

While acknowledging the need to address budget deficits in accordance with the Gramm-Rudman-Hollings Balanced Budget Act, we do not believe human service programs, including those of ADAMHA, should bear the heavy burden of further cuts. These programs have been "pared to the bone" already, and Congress must look at alternative means to control the federal deficit.

ADAMHA
(in $millions)

| | Approp. FY 90 | Pres. FY 91 | Curr. Services FY 91 | Our Proposal FY 91 |
|---|---|---|---|---|
| NIMH | | | | |
| Research | $389.6 | $413.5 | $465.2 | $579.3 |
| Research Training | $ 24.2 | $ 25.8 | $ 25.3 | $ 47.6 |
| Research Mgt./Support | $ 40.1 | $ 42.6 | $ 42.6 | $ 48.5 |
| | $453.9 | $481.9 | $533.1 | $675.4 |
| Demonstrations | | | | |
| CSP/CASSP | $ 24.3 | $ 22.8 | N/A | $ 36.0 |
| Prevention | $ 4.0 | $ 4.0 | N/A | $ 5.0 |
| Homeless | $ 6.0 | $ 6.0 | N/A | $ 6.0 |
| | $ 34.3 | $ 32.8 | $ 35.8 | $ 47.0 |
| Protection/Advocacy | $ 14.0 | $ 8.0 | $ 14.6 | $ 24.0 |
| Clinical Training | $ 13.5 | $ 5.0 | $ 14.1 | $ 29.0 |
| State Planning Grants | $ 0 | $ 0 | $ 0 | $ 10.0 |
| NIDA | | | | |
| Research | $220.6 | $258.9 | $254.0 | $291.9 |
| Research Training | $ 3.9 | $ 4.9 | $ 4.1 | $ 7.0 |
| Research Mgt./Support | $ 27.1 | $ 33.3 | $ 30.4 | $ 33.3 |
| | $251.6 | $297.1 | $288.5 | $332.2 |
| Treatment Demonstrations | $128.1 | $109.9 | $133.5 | $133.5 |
| NIAAA | | | | |
| Research | $131.6 | $137.6 | $159.2 | $170.2 |
| Research Training | $ 3.2 | $ 3.4 | $ 3.3 | $ 6.2 |
| Research Mgt./Support | $ 11.1 | $ 12.2 | $ 12.2 | $ 13.3 |
| | $145.9 | $153.2 | $174.7 | $189.7 |
| Homeless Demonstrations | $ 16.4 | $ 9.5 | $ 17.1 | $ 17.1 |
| Office of Sb.Ab.Prevention | $193.4 | $261.9 | $203.7 | $273.6 |
| Office of Trmt. Improvement | | | | |
| Treatment Programs | $133.6 | $117.7 | $139.3 | $145.6 |
| Trmt. Mgt./Support | $ 2.1 | $ 4.1 | $ 4.1 | $ 5.0 |
| ADM Block Grant | $1192.9 | $1292.8 | $1242.9 | $3000.0 |
| Homeless Grants | $ 27.8 | $ 33.7 | $ 33.7 | $100.0 |
| Buildings/Facilities | $ 0.2 | $ 3.1 | $ 3.1 | $ 3.1 |
| Office of the Admin. | $ 10.3 | $ 12.4 | $ 11.2 | $ 14.2 |

ADAMHA
(in $millions)

| | Approp. FY 90 | Pres. FY 91 | Curr. Services FY 91 | Our Proposal FY 91 |
|---|---|---|---|---|
| ADAMHA AIDS Budget (DO NOT ADD) | | | | |
| NIMH Research | $ 68.4 | $ 78.1 | $ 87.2 | $109.3 |
| NIDA Research | $ 56.5 | $ 76.5 | $ 71.7 | $ 85.3 |
| NIDA Demonstrations | $ 81.6 | $ 63.3 | $ 84.9 | $103.3 |
| NIMH Demonstrations | $ 0 | $ 0 | $ 0 | $ 12.0 |
| NIAAA Research | $ 8.2 | $ 9.2 | $ 11.2 | $ 11.6 |
| Buildings/Facilities | $ 0 | $ 1.6 | $ 1.6 | $ 1.6 |
| Off. of Administrator | $ 0 | $ 0.9 | $ 0 | $ 0.9 |
| | $214.6 | $229.7 | $256.7 | $324.0 |

NATIONAL INSTITUTE OF MENTAL HEALTH
RESEARCH
(dollars in millions)

| | FY 90 | President FY 91 | Current Services FY 91 | Our Proposal FY 91 |
|---|---|---|---|---|
| Research | 389.6 | 413.5 | 465.2 | 579.3 |
| Research Training | 24.2 | 25.8 | 25.3 | 47.6 |
| Research Mmgt. and Support | 40.1 | 42.6 | 42.6 | 48.5 |
| (Incl. AIDS) | 453.9 | 481.9 | 533.1 | 675.4 |

The National Institute of Mental Health (NIMH) is the national leadership focus for efforts to conquer the mental disorders and to improve the care of those who suffer from them. NIMH is the largest scientific institute in the world with a primary focus on mental illness. In addition to 600 investigators in its intramural research programs, NIMH provides, through its extramural programs, over 85 percent of the financial support for other U.S. research effort focused on the understanding, treatment and prevention of mental illness. NIMH supports a very broad range of research, training and knowledge dissemination activities, including; basic, clinical and mental health services research and services research demonstrations where concepts developed in laboratories can be tested in real-life situations.

To continue the great progress made in recent years -- and to begin to approach a level of effort commensurate with the national costs of mental illness -- the NIMH simply must receive support far above that envisioned in the FY 1991 President's budget. The President's budget, in fact, places in severe jeopardy the great momentum the mental health field has built over the last few years, significantly constraining ongoing research activities and ignoring the need for expanded research and research training. We recommend a significant increase in research training funds for areas of critical concern, including schizophrenia and in the neurosciences.

The President's recommendation is especially unfortunate given the unique opportunities which now exist in the neural and behavioral sciences. Recent advances in these fields place the Nation in a unique position to realize clinical advances to provide relief to countless victims of mental disorders. However, under the President's Budget, such important initiatives as the National Plan for Schizophrenia Research, the Decade of the Brain, and the new National Plan for Research on Child and Adolescent Disorders will not be realized.

Similarly, very little is known about child and adolescent disorders, and relatively little current research attention is devoted to them. Now the Institute of Medicine has sent to the Congress a major report entitled "Child and Adolescent Mental Disorders Research." This report provides specific program and policy recommendations for a national initiative to significantly expand child and adolescent mental disorders research. We support funding to implement this overdue initiative.

## NATIONAL INSTITUTE ON DRUG ABUSE (NIDA)
(dollars in millions)

| | FY 90 | President FY 91 | Current Services FY 91 | Our Proposal FY 91 |
|---|---|---|---|---|
| Research | 220.6 | 258.9 | 254.0 | 291.9 |
| Research Training | 3.9 | 4.9 | 4.1 | 7.0 |
| Res. Mgt. and Supp. | 27.1 | 33.3 | 30.4 | 33.3 |
| | 251.6 | 297.1 | 288.5 | 332.2 |
| Demonstrations | 128.2 | 109.9 | 133.5 | 133.5 |

The National Institute on Drug Abuse (NIDA) is the primary source of support in the United States for research on the treatment and prevention of drug abuse. NIDA's intramural and extramural research programs support basic, clinical, applied, and epidemiological studies of drug abuse. NIDA's research demonstration programs generate information on promising new prevention and treatment programs. NIDA also supports the training of new researchers for careers in drug abuse research and the career development of established researchers in both basic and clinical research related to drug abuse.

While the Nation has made progress in reducing the overall number of people who abuse drugs, drug abuse remains widespread, and the adverse health consequences connected to substance abuse are increasing. NIDA's research priorities for FY 1991 reflect a recognition of the serious consequences of drug abuse and the need for a long-term commitment to finding solutions in the form of new and improved prevention and treatment strategies. Stable support for research ranging from basic studies of how drugs affect the central nervous system to large scale clinical trials for new treatment medications is necessary.

It is critical that NIDA continue to place high priority on four areas of medical and behavioral research that have been identified to be of prime importance: HIV/AIDS; improving drug abuse treatment; maternal drug abuse and its effect on children; and especially, prevention. While progress has been made in reducing the spread of HIV/AIDS in homosexual males, the same cannot be said about intravenous drug abusers, who remain the most likely source of HIV infection in infants and the heterosexual population.

With funds provided by the Anti-Drug Acts of 1986 and 1988, NIDA has expanded research to improve drug abuse treatment. For example, progress has been made in treating heroin abusers with the development of pharmaceuticals that inhibit the desire to use heroin. A recent Senate Judiciary Committee Report, "Pharmacotherapy. A Strategy for the 1990's" confirmed that such addiction treatments are most effective when accompanied by concurrent behavioral therapy. Special emphasis must continue to be given to the development of new pharmacologic agents to aid in the treatment of cocaine, cocaine derivatives, and PCP. In FY 1990, NIDA will establish a new division to coordinate all of its medications development program activities which, hopefully, will be expanded in FY 1991.

The increasing use of crack cocaine by women and the increase in infants born to mothers who are IV drug users or who are the sexual partners of IV drug abusers is a matter of tremendous national concern. NIDA has greatly expanded its research in this area and we encourage continued and expanded attention in FY 1991.

## NATIONAL INSTITUTE ON ALCOHOL ABUSE AND ALCOHOLISM (NIAAA)
(dollars in millions)

| | FY 90 | President FY 91 | Current Services FY 91 | Our Proposal FY 91 |
|---|---|---|---|---|
| Research | 131.6 | 137.6 | 159.2 | 170.2 |
| Research Training | 3.2 | 3.4 | 3.3 | 6.2 |
| Research Mmgt. and Support | 11.1 | 12.2 | 12.2 | 13.3 |
| | 145.9 | 153.2 | 174.7 | 189.7 |
| Demonstrations (Homeless) | 16.4 | 9.5 | 17.1 | 17.1 |

The National Institute on Alcohol Abuse and Alcoholism, since its establishment in 1971, has been committed to the development of a knowledge base that can be used to improve the treatment and prevention of alcohol abuse and alcoholism. Through research we know that alcohol abuse is a widespread problem arising from a complex interplay of biological, psychological and environmental factors. NIAAA's research program encompasses a wide range of research in the biomedical and behavioral sciences. With so many new leads to explore about the causes, treatment effectiveness and prevention of alcoholism and alcohol problems, it is critical that adequate resources be allocated to the NIAAA.

Funding for NIAAA in 1990, which includes funds provided by the 1990 Drug Supplement, is enabling the Institute to sustain its wide array of research endeavors. Investigator-initiated efforts continue to be NIAAA's highest priority and provide the most effective means for the innovative scientific inquiry necessary to build the knowledge base for alcohol-related research. New research centers concerning alcohol abuse among children and adolescents, and treatment/patient matching will be undertaken, as well as an expansion of the generic research cooperative agreement.

NIAAA has initiated a number of research studies in a variety of areas that hold promise for expanding our knowledge regarding alcoholism and alcohol abuse and for developing effective treatment and prevention programs. The Institute has recently embarked on a major effort aimed at identifying the gene or genes that influence suspectibility to alcoholism. NIAAA-sponsored social, behavioral and neuroscientists involved in alcohol research increasingly are focusing on brain mechanisms involved in alcohol intoxication, reinforcement, tolerance and dependence. Recent findings are potentially significant. Alcohol abuse can injure many body systems. Prevention and amelioration of these consequences depends on continued research to understand the underlying neurochemical mechanism of alcohol's effects on the brain at all stages of the life cycle.

NIAAA also continues to fund a number of laboratory studies of alcohol's effects on prenatal and postnatal development. Continued and expanded research is required to determine why and how alcohol adversely affects the fetus and the mechanisms that likely contribute to fetal alcohol syndrome.

In FY 1990, $16.4 million was provided for the Stewart B. McKinney Homeless Demonstration Projects to provide the needed focus on homeless individuals with alcohol and other drug problems. We support an increase to this critical program to enhance national efforts to serve this traditionally undeserved population.

### ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION
### AIDS PROGRAMS

| FY 90 | President FY 91 | Current Services FY 91 | Our Proposal FY 91 |
|---|---|---|---|
| 214.6 | 229.7 | 256.7 | 324.0 |

The Alcohol, Drug Abuse and Mental Health Administration is the federal government's lead agency in developing new ways to prevent the spread of HIV, in dealing with the drug abuse aspects of the epidemic, and in addressing the psychosocial ramifications of the disease. Instability in funding for research and services continutes to undermine the success of ADAMHA AIDS efforts, creating a level of uncertainty for researchers and service providers alike.

We believe prevention should remain the top priority of ADAMHA. The President's budget once again fails in this regard. Insufficient research has been conducted regarding successful HIV prevention strategies among ethnic-minority homosexual and bisexual men, sexual partners of drug users, and adolescents — all of whom are becoming infected at increasing rates.

We support the important research underway regarding neuroimmunology and psychoneuroimmunology that is not undertaken by other PHS agencies. Research into the interaction of drugs of abuse and HIV and drugs and the immune system are also important new areas directly relevant to the understanding and prevention of HIV. The NIMH's work on AIDS Dementia Complex is important.

We propose that funds be provided beyond the President's request to support the following actitivies:

- $20 million to restore to the FY 1990 level of $33.6 million the drug abuse outreach demonstration programs.
- $17 million to maintain the number of new and competing prevention research grants at the FY 1990 level.
- $10 million to properly fund ADAMHA's randomized field trials of prevention interventions.
- $12 million to fund the mental health services research demonstration program authorized by Congress in P.L. 100-607.
- $20 million for community based prevention and service organizations focusing on drug users.
- $10 million for outreach training and support services for substance abuse and mental health AIDS service providers to focus on outreach workers and volunteer counselors.
- $5 million for research-services collaborative efforts, bringing together AIDS service providers and social scientists.

ALCOHOL, DRUG ABUSE AND MENTAL HEALTH BLOCK GRANT
(dollars in millions)

| | FY '90 | President FY '91 | Current Services FY '90 | Our Proposal FY '90 |
|---|---|---|---|---|
| ADMS Block Grant | $1,192.9 | $1,292.8 | $1,242.9 | $3,000.0 |

The ADMS Block Grant, established in 1981 to finance community services, was expanded and restructured as part of the Omnibus Anti-Drug Act of 1988 (P.L. 100-690). The current ADMS Block Grant consists of the previous program (alcohol, other drug abuse and mental health services), the Emergency Alcohol and Drug Treatment Block Grant, and a new emphasis on increasing treatment to intravenous drug users to reduce the transmission of AIDS.

In 1990, a total of $1,192.8 billion was appropriated, which includes the original appropriation of $790 million and an additonal $415 million for substance abuse services to implement the President's National Drug Control Strategy. Specifically, monies are available for these purposes: $895.6 million for alcohol and other drug abuse prevention and treatment services; $237.6 million for community mental health services; and $60 million for data collection, evaluation and technical assistance.

For FY 1991, President Bush proposes to fund the Block Grant at $1.292 billion, only a $100 million increase over FY 1990 levels. Of this increase, $90 million would be available for drug abuse initiatives only. The remaining $10 million is earmarked for data collection, services research and technical assistance, bringing the total dollars set aside for these activities to $74 million, 5.7 percent of the total block grant funds.

We recommend a substantial increase in the ADMS Block Grant to enable expansion in the provision of services to all three disabilities: mental health, alcohol, and other drug abuse. The mental health share of the block grant has not been increased for two fiscal years and, in fact, decreased in FY 1991. Additionally, if we are to meaningfully address the substance abuse problem in the United States, then we must make additional funding available for alcohol, as well as other drug abuse prevention, intervention and treatment services nationwide. States and local communities throughout the country have a significant and growing need for additional federal appropriations for alcohol and other drug abuse and mental health prevention and treatment services. Increased federal support to expand treatment capacity and to improve the quality of care provided is essential. Funding increases are critical to alleviate the health and social consequences of alcohol and other drug abuse and mental disorders; to increase employment and job productivity for thousands of persons; to keep families together; to reduce drug related violence, and to save hundreds of lives by reducing the rate of HIV and AIDS transmission among thousands of alcohol and other drug dependent persons, their sexual partners and their children.

NATIONAL INSTITUTE OF MENTAL HEALTH
CLINICAL TRAINING
(dollars in millions)

| | FY 90 | President FY 91 | Current Services FY 91 | Our Proposal FY 91 |
|---|---|---|---|---|
| NIMH | 13.5 | 5.0 | 14.1 | 26.0 |
| NIDA/NIAAA | 0 | 0 | 0 | 3 |

The NIMH clinical training program continues to be an important federal initiative to enhance the quality and effectiveness of services to persons with mental disorders. We support clinical training projects in the core mental health disciplines of psychiatry, psychology, social work, nursing, and marriage and family therapy and we recommend that training support be extended to the field of mental health counseling.

These projects are specially designed (1) to ensure the placement of mental health personnel in shortage areas and in public facilities, such as community mental health centers, and (2) to improve the quality of training provided to mental health professionals. Since 1981, over 3500 mental health professionals have provided national service to priority populations through this effort.

In 1989, Congress increased funding for the clinical training program for the first time in several years. Despite this action, the Bush Administration budget recommends only $5 million for the program in FY 1991 and recommends that the program be phased out after FY 1992. This is a dramatic decline from the $70 million funding level of the 1970s but there has been no corresponding decline in the nation's pressing mental health needs. Congress has consistently rejected similar Administration budget recommendations over the past decade.

Our proposed alternative NIMH funding level would enable the program to continue to support the recruitment, training, and placement of mental health professionals in shortage areas consistent with the goals of the Institute and the needs of the nation. This modest increase would enable the Institute to fulfill the Congressional mandate to address the mental health needs of ethnic minorities, the long-term seriously mentally ill, children and adolescents, and the elderly — all underserved populations. Our proposal would permit increased support for student trainees committed to working with these populations, and the development of specially trained faculty, well grounded in modern mental health diagnostic and research techniques and community-based care delivery.

We also propose that $3 million be provided under a separate line item for NIAAA/NIDA Clinical Training, to ensure that alcohol and drug abuse education becomes an integral part of the training received by all health and mental health professionals. Congress provided $754,000 for this effort in FY 1989. The future success of our research efforts and our ability to meet the critical needs associated with substance abuse is dependent on our ability to recruit qualified personnel who can conduct clinical trials of new behavioral and pharmacologic approaches to these problems.

NATIONAL INSTITUTE OF MENTAL HEALTH
MENTAL HEALTH SERVICES DEMONSTRATIONS
(dollars in millions)

| | FY 90 | President FY 91 | Current Services FY 91 | Our Proposal FY 91 |
|---|---|---|---|---|
| Demonstrations | | | | |
| CSP/CASSP | 24.3 | 22.8 | | 36.0 |
| Prevention | 4.0 | 4.0 | | 5.0 |
| Homeless | 6.0 | 6.0 | | 6.0 |
| | 34.3 | 32.8 | 35.8 | 47.0 |

The National Institute of Mental Health (NIMH) demonstration programs recognize the importance of effective, comprehensive, community-based systems of care for individuals with severe and chronic mental illness. In FY '90, authorization for prevention and rural mental health demonstration programs was added. Originally designed to serve adults, the Community Support Program (CSP) was expanded in 1983 to include the Child and Adolescent Service System Program. By 1985, demonstration programs for homeless persons with mental illness were added, and a year later demonstrations were funded for elderly person with mental illness. In 1987, substance abuse was added to the mental illness demonstration programs for young adults. Each year, technical assistance has been developed to assist states and communities in the planning and implementation of the grants.

The Administration has called for a $1.5 million decrease in funding for mental health services demonstrations at a time when mental health professionals and advocates are testifying for the effectiveness and efficiency of an expanded community continuum of care for adults and children. In order to provide current services a minimum of $35.8 million, or a 4.2 percent increase is needed. Our professional judgement budget calls for a 33.3 percent increase ($47.0 million) for demonstrations.

Our recommendation is based on sound professional judgement. The CSP demonstration program's necessity and effectiveness requires the expansion from 200 to at least 241 demonstrations for new, competing, supplemental and continuing grants. In FY 1991, support will be needed for services programs meeting the special needs of elderly persons with severe mental illness, which is the fastest growing population diagnosed with mental disorders; for youngsters with a dual diagnosis of mental illness and substance abuse, especially those with unstable living conditions; and for searching out cost-effective programs that coordinate the use of existing community resources.

We recommend $5 million for a mental health prevention services demonstration program in FY 1991. Research has identified a number of factors which place people at risk for developing serious mental health problems and mental illness. By providing focused assistance and attention to these vulnerable groups, prevention programs seek to provide the "edge" needed to maintain mental health and avoid mental health problems during difficult transitions.

NATIONAL INSTITUTE OF MENTAL HEALTH
PROTECTION AND ADVOCACY FOR PERSONS WITH MENTAL ILLNESS
(in millions)

| FY 90 | President FY 91 | Current Services FY 91 | Our Proposal FY 91 |
|---|---|---|---|
| 14.0 | 8.0 | 14.6 | 24.0 |

The Protection and Advocacy System for Persons with Mental Illness (PAMI) was established in FY 1986 and reauthorized in 1988. Funds are provided on a formula grant basis to existing Protection and Advocacy (P&A) Systems for persons with developmental disabilities to protect and advocate for persons with mental illness and to investigate complaints of abuse and neglect in mental health facilities. These facilities include: public and private hospitals, nursing homes, group homes, and board and care homes. Individuals with mental illness are also eligible for services within 90 days of discharge from a facility. In the new reauthorization, persons in jails and detention centers were added, as well as incidents of abuse and neglect while being transported to a system. The P&A System must have an advisory board of persons expert in mental health issues, composed of a majority of consumers and their families. PAMI's represented approximately 18,600 clients in 1989, an 85% increase over 1988.

The President's budget proposes to "phase-out" federal support for the PAMI program over the next three years. This assumes that the states will assume responsibility for funding and operating the program. Since PAMIs often are called upon to investigate and attempt to correct instances of abuse and neglect of residents by staff in state-operated mental health institutions, it is unlikely many states will continue funding the program on their own. The consequence of the President's phase-out proposal would be a patchwork of state-funded PAMIs at best and the program's total destruction at worst.

The establishment of the Protection and Advocacy System for Persons with Mental Illness has demonstrated the critical need for advocacy services for a neglected population. The program is guided by an advisory board with a majority of consumers and family members who jointly develop priorities for service. The program must experience major growth to ensure quality advocacy services to the large number of persons living in institutions who cannot be served at the present appropriation level. Programs report representing persons with mental illness in a variety of settings including state correctional facilities, nursing homes, and board and care homes. The addition of the new service mandate for 1989 as well as the ever-increasing demand for services from nursing homes, board and care homes and large state hospitals require a substantial increase in funding.

We recommend an appropriation of $24 million, for the Protection and Advocacy Program for Persons with Mental Illness in FY 1991.

## NATIONAL INSTITUTE OF MENTAL HEALTH
## COMPREHENSIVE PLANNING FOR SERIOUSLY MENTALLY ILL INDIVIDUALS

| FY 90 | President FY 91 | Current Services FY 91 | Our Proposal FY 91 |
|---|---|---|---|
| 0 | 0 | 0 | 10 |

Public Law 99-660, passed in 1986, authorized grants to states to develop plans to establish and implement "an organized community-based system of care for chronically mentally ill individuals." Ten million dollars were authorized for each of FY 1988 and FY 1989. The grants were not re-authorized in FY 1990.

Since there is not yet an authorization for the Comprehensive Planning for Seriously Mentally Ill Individuals Act for FY 1991, the President's Budget does not request funding. While states have continued implementation of their comprehensive plans, there is concern that they are hampered by the lack of planning monies currently available. The planning funds serve an extremely valuable function in enabling states to share information and resources with other states in conducting plan development activities. Additionally, these funds enable states to access technical assistance from the National Institute of Mental Health (NIMH) in developing their state plans. Although the grant program was limited in FY 1988 and 1989, it enabled states to marshall resources otherwise unavailable for planning activities.

We recommend that $10 million for State Planning Grants for Persons with Serious Mental Illness be reauthorized and appropriated in FY 1991.

Few states are achieving a comprehensive care system for persons with serious mental illnesses. Funding this law at the previously authorized level will provide incentives to states (and their citizen advocates) to better define the problems and mobilize the political will within each state to undertake needed changes. PL 99-660 requires broad community participation in the development of these comprehensive plans (including involvement of consumers, families, citizen advocates, providers, and public agencies). State plans offer the opportunity to bring together divergent funding streams and programs in order to promote interdepartmental coordination and cooperation. The minimal federal financial incentive requested will assist states in carrying out the intent of Congress when it enacted this mandate.

## OFFICE OF SUBSTANCE ABUSE PREVENTION
(dollars in millions)

| | FY 90 | President FY 91 | Current Services FY 91 | Our Proposal FY 91 |
|---|---|---|---|---|
| Demonstration Projects | 155.6 | 220.3 | 162.4 | 230.0 |
| Training | 26.0 | 26.9 | 27.1 | 28.0 |
| Program Management | 11.8 | 14.7 | 14.1 | 15.6 |
| Total | 193.4 | 261.9 | 203.7 | 273.6 |

The Anti-Drug Act of 1986 (P.L. 99-690) significantly expanded the scope and functions of OSAP, and designated it an equivalent institute within ADAMHA. Three new grant programs were developed and OSAP assumed responsibility for a national training system for prevention and treatment personnel.

Of the amount appropriated for OSAP for FY 1990, $155.6 million was mandated for demonstration projects. The high risk youth program was designed in 1987 to develop and test innovative strategies to minimize the occurence of substance abuse problems among high risk youth. In FY 1990, a total of 156 high risk youth grants are being funded, 123 of which are new. Under the President's budget proposal, only 18 new grants will be funded.

OSAP initiated a new program in FY 1989 designed to develop innovative community-based models of education, prevention, and/or treatment for substance abusing pregnant women and their infants. In FY 1990, a total of 120 grants are being funded, 98 of which are new. The President's budget proposal would enable only 15 new grants to be awarded.

OSAP recognizes that its overall prevention and intervention strategy will be most effective if it assists communities to develop comprehensive, collaborative, and systematic approaches that emphasize local community involvement. Initiated in FY 1990, the Community Prevention Partnership program is designed to stimulate the formation of local coalitions, consortiums and partnerships for the purpose of developing comprehensive, multi-disciplinary prevention systems within local communities. A total of 24 new grants will be awarded in FY 1990 with no new grants recommended for FY 1991.

Authorized under the Anti-Drug Abuse Act of 1988, the Community Youth Activity Program provided funding to communities to establish and evaluate innovative prevention services programs for youth, especially those not in school, at risk of dropping out or involved with gangs. In FY 1990, 97 Community Youth Activity grants are being funded. Under the President's FY 1991 budget, no new grants would be awarded.

The OSAP National Training System was initiated in September 1989 to build a comprehensive training capability. In FY 1990, $26 million is provided to increase training for health professionals, community organizations and trainers, as well as training related to pregnant women and their infants. The President's budget calls for no new initiatives.

OFFICE FOR TREATMENT IMPROVEMENT
(dollars in millions)

| | FY 90 | President FY 91 | Current Services FY 91 | Our Proposal FY 91 |
|---|---|---|---|---|
| Waiting List Grants | 64.3 | 0 | N/A | N/A |
| Treatment Improvement Grants | 39.6 | 85.6 | 103.6 | 108.0 |
| Treatment Grants to Crisis Areas | 29.7 | 32.1 | 36.1 | 40.0 |
| Homeless Grants | 27.8 | 33.7 | 33.7 | 100.0 |
| Program Management | 2.1 | 4.1 | 4.1 | 5.0 |
| Total | 163.5 | 155.5 | 177.5 | 193.0 |

The Office for Treatment Improvement (OTI) was created in FY 1990 to provide a focus within ADAMHA to meet the growing federal effort to promote and enhance programs and new approaches in the treatment of drug abuse and the associated problems of alcoholism and mental illness. OTI is also expanding treatment capacity through its management of the ADMS Block Grant and provision of financial assistance for 1) targeted expansion in high intensity areas of drug abuse and 2) specialized treatment programs for substance abusing women of child bearing age and their children, adolescents, minorities, residents of public housing, and individuals with multiple drug, alcohol, and mental health problems. OTI also collaborates with States, local communities, health care providers and national organizations to upgrade the quality of treatment and improve the effectiveness of specific treatment programs.

OTI now has the responsibility to develop and manage several grant programs focusing on areas of critical need. The Waiting List Reduction Grant program was created in FY 1989 to help alleviate the national shortage of drug treatment slots and services. A total of $100 million was authorized by Congress to be available until expended. ADAMHA funded about $100 million in FY 1989 and FY 1990. This provided approximately 20,000 new treatment slots at an average cost of $5,400 each. The balance of the FY 1990 appropriations, $39.3 million, requires new authorization before OTI can obligate these funds. The program is also not authorized in FY 1991. In addition, the Administration prefers to expand treatment capacity using the block grant mechanism and estimates that 11,000 new drug treatment slots will be made available through the block grant in FY 1991.

OTI has also initiated Treatment Grants to Crisis Areas to provide financial and technical assistance to selected urban areas that have been identified as having a high prevalence of drug abuse. The purpose of targeted assistance to these cities is to improve the quality and effectiveness of drug treatment services and to promote necessary coordination among various public and private service agencies.

In FY 1990, $39.6 million was appropriated for Treatment Improvement Grants to assist providers in improvement of treatment opportunities and outcomes. The Administration has requested $45.6 million to continue the activities begun in FY 1990 and an additional $40 million for expanding programs focusing on high risk populations.

BLOCK GRANT PROGRAM
SERVICES TO HOMELESS INDIVIDUALS
WHO ARE SERIOUSLY MENTALLY ILL
(in millions)

| FY 90 | President FY 91 | Current Services FY 91 | Our Proposal FY 91 |
|---|---|---|---|
| 27.8 | 33.7 | 33.7 | 100.0 |

The McKinney Homeless Assistance Amendments Act of 1988 (PL 100-268) reauthorizes through 1992 formula grants to states to provide mental health services to homeless people with serious mental illness. The Act authorizes $35 million for FY 1991 and "such sums as may be necessary" for FY 1992. To receive the grant, states are required to provide outreach, and supervisory services in residential settings. States must match $1 for every $3 of federal support. Currently, all states participate in the program which is designed to address the major problems of homeless people with serious mental illness, including resistance to traditional mental health services in organized care settings; violence; erratic behavior; and serious medical problems as infectious disease and malnutrition.

The budget request of $35 million to "fully fund" the program is inadequate to meet the extensive needs of homeless people with mental illness. A recently completed survey of 48 states and the District of Columbia (New York and South Carolina did not report) reveals that states are serving no more than 20 percent of the homeless population with mental illness, totaling only 350,000 people. A substantial increase is necessary in FY 1991 above the President's request to enable states to begin to more adequately meet the desperate needs of homeless people who are mentally ill.

We recommend $100 million to continue and expand the state grant program of mental health services to homeless individuals.

The McKinney Act state grant was carefully designed to target services most helpful in addressing the unique needs of homeless people with serious mental illness. No other federal support program provides significant assistance to this needy population. While the only other mental health community service program, the Alcohol Drug Abuse & Mental Health (ADM) Block Grant is of some help, it also is inadequately funded and not targeted. Medicaid is not generally available to adults without families who are not SSI-eligible. States have indicated their ability and willingness to match the federal grants at significantly higher levels. Our recommendation of $100 million exceeds the current authorization to emphasize the urgency of the service needs of homeless people who are mentally ill.

Senator HARKIN. Let me ask you one question. As a percent of children—or as a parent of a child of serious mental illness, what services are most important to you and your family? What would you suggest that NIMH could do to help you and the thousands of other families in your situation? What services are most important?

Ms. STOUT. I would say that having outpatient services available, group homes, research, which is why we are here today, obviously research, to find better medications to prevent tardive dyskinesia, more mental illness professions, folks that understand that mental illness is a serious disease, the same as cancer, diabetes. As Senator Simon mentioned a little bit ago, it is something that folks just have not talked about.

Senator HARKIN. OK, we will try to get adequate funding in again this year. Did you have anything you wanted to add?

Ms. FLYNN. Only to thank you again for your leadership on this issue, Senator. We have just begun to catch up in the last several years with your help on what has been a serious underfunding of this research, and as Senator Simon said, directly related to the unfortunate stigma that it still attaches to what are now clearly, because of the research we have been able to get, being seen as brain diseases.

Just last week, the New England Journal of Medicine published a groundbreaking report showing that schizophrenia actually can be detected through structural abnormalities in the brain. These are serious, disabling, biological illnesses, and we really need to catch up and find out a lot more, not only about the causes, but better treatments and better resources in the community, so that we do not have so many homeless; so that we do not have so many folks falling through the cracks. So we really have appreciated your help in the past and really need to keep that momentum going.

Senator HARKIN. We are doing our best. What number did you have?

Ms. FLYNN. Our non-AIDS request, the total request I think we have is 675. I think the non-AIDS is $193 million increase, going to a total—let me try to find my numbers on here—going to a total of 520, 525.

Senator HARKIN. We have a request for 439 from the administration.

Ms. FLYNN. We hope that you can encourage them to be a little more generous.

Senator HARKIN. Well, if we can get our budget allocations up.

Ms. FLYNN. Someone said to me it is less than the amount of one B-1 bomber. I think in light of your earlier comments, that may be the way to discuss it.

Ms. STOUT. May I add one more thing? We are going to have the D/ART Program coming to Iowa, which is depression awareness, which we hope will get to the communities like Dubuque County and others to alert them to depression as an illness.

Ms. FLYNN. This is an NIMH educational program, based on the science we now have that helps to remove some of the shame that keeps people from seeking treatment. A very effective public outreach effort that is coming to Iowa.

Senator **Harkin**. Thank you very much.

## STATEMENT OF GERALD KLONGLAN, CHAIRMAN, DEPARTMENT OF SOCIOLOGY, IOWA UNIVERSITY ON BEHALF OF THE CONSORTIUM OF SOCIAL SCIENCE ASSOCIATIONS AND THE FEDERATION OF BEHAVIORAL, PSYCHOLOGICAL AND COGNITIVE SCIENCES

Senator **Harkin**. Next is Professor Gerald Klonglan, chairman, Department of Sociology, Iowa University, here on behalf of the Consortium of Social Science Associations.

We welcome you, Dr. Klonglan.

Dr. **Klonglan**. Today, I would like to focus attention on the need for increased funding for social and behavioral science research at the National Institutes of Health. And our written statement also includes recommendations about ADAMHA and the Agency for Health Care Policy and Research. Our scientific research, as well as common logic, makes it increasingly clear that health is not solely a medical issue. And so to promote good health and to deal with many of the needs to understand problems, we need to focus on personal and societal factors, in terms of health-related concerns, particularly as we look at human development and aging.

Addressing rural health problems as a subset—there are many subsets, but that is one. At Iowa State we have recently established a social and behavioral research center for rural health. And we are—with Health and Human Services funding we are trying to look at several very critical problems: farm families' response to economic stress like we have just heard, drug use by rural adolescents, the homeless people in the cities coming out of the rural areas and a lot of the parenting problems in rural populations that are increasing.

Our research takes a historical perspective, looking at Depression era farm problems and relates them to today's and the differences, and then new challenges and new solutions that are needed.

I would like to turn to some specific recommendations now as it relates to research and NIH. We are very much interested in seeking a total of $9.237 billion for NIH, which as we know, with the exception of AIDS and the human genome program, have been really limited in growth in the past few years.

Now another thing that we are very interested in is increasing the amount of funds for the social and behavioral sciences, because only about 3.6 percent of the total NIH budget really goes to health and behavioral research. And we really—one of our key recommendations is to strongly recommend that NIH establish explicit annual goals to raise its expenditures for this research to a target level of doubling during the next 3 years. That is one of the key things for social/behavioral research.

Now the changing demographics make it imperative that we also increase the support for the National Institute on Aging. There are three major areas that we are very much interested in: increased funding for long-term care, to try to understand—this is research for long-term care; research on the interaction of work, retirement and health—it is a major, major focus; and third, we are very much interested in age-related changes in cognitive and behavioral functioning, and, again, we get into Alzheimer's and the need to really understand that to a greater extent.

And finally, in terms of the National Institutes of Child Health and Human Development, we have two major areas as we increase the need for research. One looks at the injury prevention effort, a new effort that has been started but has not been able to be funded very much. And also we have a beginning research program in terms of infant day care, and again, we need significant funds to help increase that particular activity.

### PREPARED STATEMENT

And although in fiscal year 1991, in terms of appropriations, as not required, we urge the subcommittee to again make explicit its support of survey of health and AIDS risk prevalence.

So with that, I will stop and thanks for this opportunity to present some of the key areas where we need additional social/behavioral sciences research support in NIH.

[The statement follows:]

# STATEMENT OF GERALD KLONGLAN, CONSORTIUM OF SOCIAL SCIENCES ASSOCIATIONS, CHAIRMAN, DEPARTMENT OF SOCIOLOGY, IOWA UNIVERSITY

Mr. Chairman and Members of the Subcommittee, I am Dr. Gerald Klonglan, chairman of the Department of Sociology and Anthropology at Iowa State University. I speak today on behalf of the Consortium of Social Science Associations (COSSA) and the Federation of Behavioral, Psychological and Cognitive Sciences. COSSA represents over 185,000 scientists across the broad range of social and behavioral science disciplines. The Federation is a coalition of 15 scientific societies and 130 university departments. Membership lists for both of these organizations are attached to this testimony.

Today, I would like to focus attention on the need for increased funding for social and behavioral science research throughout the Department of Health and Human Services (HHS). I give particular attention to appropriations for the National Institutes of Health (NIH) as well as the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) and the Agency for Health Care Policy and Research (AHCPR).

Scientific research and common logic make it increasingly clear that health is not solely a medical issue. If, as a nation, we wish to promote good health and improve treatment of illness and disability, we must gain a better understanding of how personal and societal factors affect health-related concerns and influence the course of human development and aging.

How are health, behavior, and society related? Individuals' behaviors and attitudes significantly influence their ability to maintain good physical and mental health, to prevent future disease, to cope with illness and disability, and to function to their fullest potential. Society's response to health problems has broad ramifications for the national economy and the availability and quality of health care services. Changing demographics alter risks for disease, the composition of social and family support systems, and demands on the health care system.

Addressing the health problems of a heterogenous yet comparatively disadvantaged rural population offers a good example of how integrating the social and behavioral sciences into health research can benefit our citizens. In rural America, social and environmental factors -- isolation from other people, inadequate health care and public transportation as well as high levels of poverty -- compound problems of health and lifestyle. Research directed at these issues promises not only to improve health but also to mitigate the problems of isolation and to improve the functioning and quality of life of rural people.

Iowa State University has established the Social and Behavioral Research Center for Rural Health to address related issues. With HHS funding from the National Institute of Mental Health, the National Institute on Drug Abuse, and the Health Resources and Services Administration, we are looking at the impact of economic and political conditions on rural life. Our scientists are studying pressing problems -- resilience of farm families to economic stress, drug use by rural adolescents, and parenting skills in rural populations. Our research takes a historical perspective, relating depression-era farm problems to today's conditions.

## NATIONAL INSTITUTES OF HEALTH

The NIH budget, with the exception of AIDS and the Human Genome Program, has seen limited growth in the past few years. Consistent with the Ad Hoc Group for Medical Research Funding, we call for $9.237 billion for NIH in FY 1991. We believe that the specific requests outlined here fall within that level of funding.

We are concerned that the proposed NIH budget does not provide adequate support to maintain, no less expand, research project grants, contracts, and centers in areas unrelated to genome research or AIDS. Particularly troubling is the continued "downward negotiation" of grants; this practice must stop. We further believe that NIH must strengthen its support for research training, increasing both the number of slots available and allowable compensation. The social and behavioral sciences, like the biomedical sciences, anticipate a future pinch from an aging pool of researchers and increased difficulty in attracting the brightest new minds into scientific research.

### Health and Behavior Research at NIH

Health and behavior research comprises the largest component of NIH support for the social and behavioral sciences. NIH, through its inter-institute Working Group on Health and Behavior, has stated, "Many medical problems, including heart disease and cancer, appear to be influenced by social and behavioral variables, such as habits of living; by social environments (work, family, community); and by what has been termed psychosocial stress." However, despite this strong rhetoric and recent support by the Senate Appropriations Committee, for which we commend you, funding for health and behavior research has remained relatively stable, at less than 4 percent of the total NIH budget.

Although last year this Subcommittee called upon NIH to "establish a comprehensive 10-year plan for steadily increasing (its) commitment" to health and behavior research, the administration's proposed budget allocates only $285.6 million, 3.6 percent of the total NIH budget, for this research. The health and behavior budget is increased 4.5 percent above FY 1990 levels, comparable to the overall NIH budget increase of 4.7 percent (including AIDS). We strongly recommend that NIH establish explicit annual goals to raise its expenditures for health and behavior research to a target level of doubling during the next three years, with a similar rate of growth for the remainder of the decade.

### National Institute on Aging

Changing demographics make it imperative that we increase our attention to the health, lifestyle , and - effective functioning of older people. Nonetheless, the National Institute on Aging (NIA) is one of the most poorly funded NIH institutes, with only 17 percent of approved projects expected to be funded in FY 1991. Of particular concern is the low level of attention paid to the social and behavioral sciences, despite NIA's explicit mandate to fund research in these disciplines.

Research has made clear that, contrary to popular belief, older people can modify health-related behaviors and lifestyles through targeted social and behavioral interventions. Considerable expansion is needed to support this research area that promises to increase longevity and improve functioning. We recommend an additional $20 million targeted for health and behavior research at NIA.

Caring for the growing elderly population is putting an increasing financial, psychological, and social burden on families and on our health care facilities, a problem that is particularly acute when dealing with Alzheimer's patients. We recommend an additional $28 million to expand on-going social and behavioral research on the long-term care needs of older people and their families.

As longevity increases, work and retirement gain broader significance for the individual and for the national economy. How to sustain productivity of individuals wishing to remain in the work force and effective functioning for those choosing to retire are key issues requiring additional study. We recommend $6 million be added to the NIA budget for research on work, retirement, and health, including the additional $1.5 million required to implement fully the longitudinal Health and Retirement Survey mandated by Congress in FY 1990.

Further research also is required to characterize age-related changes in perception, cognition, movement, and sleep patterns. We recommend an additional $4.4 million for research on cognitive and behavioral functioning that will allow us to foster independent living, to dissociate normal aging from disease states, and to plan effective interventions.

**National Institute of Child Health and Human Development**

The National Institute of Child Health and Human Development (NICHD) provides focus for research on the psychological and social factors influencing human development from conception through adulthood. Despite its broad and important mandate -- assuring the health and well-being of children and mothers -- the administration's budget recommendation is based on low approval rates and unacceptably high negotiated reductions, particularly for the centers program. We recommend that Congress fund NICHD at $635.3 million in FY 1991, an amount the scientific and medical community believes is required to cover actual costs of research that should and can be conducted.

The administration's budget would significantly limit many social and behavioral research initiatives, many of which have been specifically requested by Congress. Additional FY 1991 monies are necessary to ensure that NICHD's well-coordinated injury prevention effort, expanded at congressional directive, is not funded at the expense of other important programs. Further, without additional funds, NICHD will not be able to take full advantage of its infant day care research network, expanded in FY 1990 at the request of Congress.

The proposed budget also would restrict promising areas of research central to the NICHD mission: applying social and behavioral science research strategies to children's health problems; understanding how children develop cognitive skills -- thinking, learning, and communicating -- as well as how they grow socially and emotionally; and identifying demographic factors influencing trends in national birth rates, the family, and the spread of sexually transmitted diseases, including AIDS. Without additional funds for the contract mechanism line, NICHD will be limited in its ability to implement a major study evaluating the effectiveness of the full range of intervention strategies used to reduce teen pregnancies.

Although an FY 1991 appropriation is not required, we urge the Subcommittee to again make explicit its support of the Survey of Health and AIDS Risk Prevalence. Data from this feasibility study have broad public health implications, which range from stemming the spread of sexually transmitted diseases, including AIDS, to halting the alarming rate of teenage pregnancies. We are deeply troubled that political ideology is interfering with the conduct of this and other peer-reviewed studies at NICHD.

## ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH ADMINISTRATION

Responding to the personal and societal crises related to substance abuse and mental health demands a strong national commitment to research. We, therefore, recommend $1.197 billion for research and research training at ADAMHA.

Existing treatment and prevention approaches simply are not adequate to address the full scope of the problem. While we applaud the advances made in molecular biology and neuroscience toward understanding the mechanisms of dependence and mental illness, we are concerned that these approaches neglect the role sociocultural and environmental factors, personality, and emotions play in promoting mental health and avoiding substance abuse.

In this "Decade of the Brain," we must not forget the relationship between the brain and behavior. We are encouraged by recent decisions within the National Institute of Mental Health to reorganize its basic research program to better reflect the importance of these areas of research. We urge Congress to support this and other efforts by directing ADAMHA to increase its support for the social and behavioral sciences by $80 million annually. The recommendation endorses the considered findings of the National Academy of Sciences, as outlined in "The Behavioral and Social Sciences: Achievements and Opportunities" and as noted by this Subcommittee in its FY 1990 appropriations report.

## AGENCY FOR HEALTH CARE POLICY AND RESEARCH

Assessing health care effectiveness and costs is not simply a matter of cost containment. Social and behavioral variables -- pain perception, ability to return to work, and the effect of care on family interactions -- must be evaluated if we are to consider health care outcomes from a patient's perspective. Such consideration is warranted as psychosocial factors such as compliance and motivation directly influence medical effectiveness.

We recommend that AHCPR be directed to allocate some of its resources to the study of social and behavioral factors affecting medical effectiveness. We further urge Congress to encourage AHCPR to enter into cooperative agreements with other research agencies within the Public Health Service, such as the National Institute on Aging which has particular expertise in conditions of older people, including Alzheimer's disease, and an established research portfolio in psychosocial aspects of medical effectiveness.

Further, we endorse the administration's recommendation of $10.505 million for activities concerning the organization, impact, efficacy, and cost effectiveness of health care services and financing systems for the care of individuals with AIDS/HIV-related disease, as outlined in S. 2240, the Kennedy-Hatch CARE Act.

# CONSORTIUM OF SOCIAL SCIENCE ASSOCIATIONS

## MEMBERS

American Anthropological Association
American Economic Association
American Historical Association
American Political Science Association
American Psychological Association
American Sociological Association
American Statistical Association
Association of American Geographers
Association of American Law Schools
Linguistic Society of America

## AFFILIATES

American Agricultural Economics Association
American Assembly of Collegiate Schools of Business
American Association for Public Opinion Research
American Educational Research Association
American Psychological Society
American Society of Criminology
Association for Asian Studies
Association for Social Sciences in Health
Eastern Sociological Society
Gerontological Society of America
History of Science Society
International Studies Association
Law and Society Association
Midwest Sociological Society
National Council on Family Relations
National Council for the Social Studies
North Central Sociological Association
Northeastern Anthropological Association
Operations Research Society of America
Population Association of America
Regional Science Association
Rural Sociological Society
Social Science History Association
Society for the History of Technology
Society for Research on Adolescence
Society for Research in Child Development
Society for the Scientific Study of Religion
Southern Sociological Society
Southwestern Social Science Association
Speech Communication Association
The Institute for Management Sciences

## CONTRIBUTORS

American Council of Learned Societies
Arizona State University
Boston University
University of California, Berkeley
University of California, Los Angeles
University of California, San Diego
University of California, Santa Barbara
Carnegie-Mellon University
Center for Advanced Study in the Behavioral Sciences
University of Chicago
University of Colorado
Columbia University
Cornell Institute for Social and Economic Research
Cornell University
Duke University
Florida State University
University of Georgia
Harvard University
Howard University
University of Illinois
Indiana University
Institute for Social Research, University of Michigan
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Massachusetts Institute of Technology
Maxwell School of Citizenship and Public Affairs, Syracuse University
University of Michigan
University of Minnesota
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National Opinion Research Center
University of Nebraska
New York University
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University of Pittsburgh
Princeton University
Rutgers University
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University of Southern California
Stanford University
State University of New York at Stony Brook
University of Tennessee, Knoxville
Texas A & M University
Tulane University
University of Virginia
University of Washington
University of Wisconsin, Madison
University of Wisconsin, Milwaukee
Yale University

## FEDERATION OF BEHAVIORAL, PSYCHOLOGICAL AND COGNITIVE SCIENCES

### Federation Member Societies

American Educational Research Association
American Psychological Association
American Psychological Society
Cognitive Science Society
International Society for Developmental Psychobiology
National Academy of Neuropsychologists
Psychometric Society
Psychonomic Society
Society for Computers in Psychology
Society for Judgment and Decision Making
Society for Mathematical Psychology
Society for Psychophysiological Research
Society for Research in Child Development
Society for Research in Psychopathology
Society of Multivariate Experimental Psychology

Senator HARKIN. Dr. Klonglan, thank you.

The subcommittee has a history of calling for more behavioral research. We did in the 1980's. Why do you think we do so poorly in this area? The Federal Government?

Dr. KLONGLAN. I think it relates to the historical developments to the health research world, which are primarily focusing in terms of biologists and the emphasis in terms of the medical and the social/behavioral sciences came along later in the history. And it has been very challenging to try to present the benefits that can occur from social science— behavioral science research.

And with the difficulties in terms of budget and resources, it is hard to add onto the social sciences because they are still so many demands in terms of the medical arena as well. So it really again comes into priorities. We think that the social/behavioral sciences can contribute significantly more. There are many good projects that cannot be funded or they have been funded, but had to be reduced substantially. And so again we have difficult challenges in doing some of the ongoing, very priority research.

Senator HARKIN. One good example is changing the behavior of people with regards to smoking. Who is doing that? Look how we are able to cut down on the incidence of lung cancer that we see coming along, emphysema, everything else because people have been changing their habits on smoking.

Dr. KLONGLAN. That is correct. There is research that has been done that we know has been very, very effective in terms of the health of the American people. And we can do a lot more research to provide additional insights to continue that, we think, very significantly, as we look to the future.

Senator HARKIN. Dr. Klonglan, thank you very much. We appreciate your being here.

### STATEMENT OF WANDA BIGHAM, PRESIDENT, MARYCREST COLLEGE, DAVENPORT, IA

Senator HARKIN. Dr. Wanda Bigham, president, Marycrest College, Davenport, IA. This is Iowa day here today. No wonder I am chairing today. [Laughter.]

I was wondering what I am doing here today.

Dr. BIGHAM. I am delighted that you are here, and I thank you for allowing me to come in.

As you noted, I am president of Marycrest College. I would like to also note that my first administrative position was as director of Upward Bound, Special Services, and Talent Search Programs at Moorehead State University in Kentucky. I have also been the first treasurer of the National Council of Educational Opportunity Associations.

I am, myself, a low-income, first-generation college student, who was lucky at the time to receive attention from some individuals who made it possible for me to go on to college, but I know that my colleagues in high school, grade school did not have that opportunity.

I know firsthand the difference that the Trio Programs make, and I am here to speak in their behalf. Trio Programs as you know, are part of the title IV of the Higher Education Act. Trio is the popular name for the programs, including Upward Bound, Special Services, Talent Search. Since then, other programs are added and they are called Special Programs for Youth from Disadvantaged Backgrounds.

The current situation with the Upward Bound, Talent Search, other Trio programs, is that there are 1,453 projects in 900 colleges and universities and 80 community agencies serving an estimate 500,000 youth and adults, seventh grade through college. This is 5 percent—5 percent of the eligible population for these programs. When I think of the difference this makes in the lives of these individuals as they receive an education and as they become productive members of society, the thought that we are serving only 5 percent is a great injustice.

I want you to know that the administration request for next year includes a $27.9 million increase to a mark of $269 million, and I applaud that. They have also included some new initiatives that relate to science and math, they have backed up the Educational Talent Search Program to include seventh and eighth graders, so that we are reaching out to students earlier to keep them in college.

I want to, instead, ask for a mark of $508 million to double the numbers of students who can be served, reminding you that this still only brings it to 10 percent of those who are eligible. At my own institution we have no special services program, for instance. We estimate that there are 700 students who are eligible and who would benefit from that.

While the need is great right now, I think the imperative increases as our demographic situation changes in this country. We are going to have more youth coming from low income families, as the birth rate declines at the middle-and the upper-income families. And part of the scary thing about this is that our work force in the future is going to come—the increases will come predominantly from this new population: youth who come out of a low-income and minority background. Already we know they are less likely to stay in school. They are less likely to go to college. The loss in human potential is great.

So I am making a request to you for a $508 million request for this purpose. That is a bold request. I make no apologies for it. The need is great. The payoff is great. The payoff is great in that, as these individuals become productive members of society, and many of the ills of society are solved, and our country can maintain its economic position in the world, and that, as you know, is threatened.

So I make this request. I hope you will consider it carefully, and consider those youth who do not have the opportunities that many in this country have.

Senator **Harkin**. Thank you very much. That is about a doubling—well, not quite a doubling of what we had last year.

Dr. **Bigham**. It is a little over a doubling as a matter of fact, $241 million to $508 million. The shocking thought that only 5 percent are served and that the statistics show the effectiveness.

Senator **Harkin**. So that would just go up to 10 percent. But now, let me ask you this. We have had these for a long time. Have there been longitudinal studies done?

Dr. **Bigham**. The Research Triangle Institute has studied Upward Bound and shown that those students stay in high school, graduate from college at a rate that is four times greater than students like them. Systems Development Corp. has done studies that indicate that special services students stay in college and graduate at a rate that is twice the rate of other students like them who enter colleges.

So their effectiveness is shown. I have had an opportunity to see the individual, and the families—the spinoff is tremendous. I can tell you about families who, once one student gets the idea of going to college, the brother or the sister—I have even had a mother come to me on a parents' day and very hesitantly say, "Do you think I could go to college? My husband is increasingly disabled." She is now a teacher in Kentucky.

And so the spinoff to even the parents, but to the brothers and sisters, in particular, and to the cousins, the friends of these individuals—it has a very great spinoff effect that has not been measured, but I know it personally.

Senator **Harkin**. Yes; so do I. Could the system itself handle a doubling? A lot of times when you double the money, you cannot handle that much. Do you think the system could handle a doubling?

Dr. **Bigham**. I have no doubt that the system could handle it. There are many institutions that would like to have an opportunity to serve in this regard whose grants do not get funded, and the institutions that already have programs are serving only a small portion of the numbers who are eligible.

We have an Upward Bound Program, for instance, who serves 60 students in the Quad Cities area. You know there are more than 60 students who have needs and who meet the criteria for low income and/or first-generation college student. So I have no doubt but that the system could handle it.

Senator **Harkin**. We will do our best.

Dr. **Bigham**. I thank you very much. It is good to be with you.

Senator **Harkin**. Thank you very much, Dr. Bigham.

### STATEMENT OF R. CREIG SLAYTON, DIRECTOR, IOWA DEPARTMENT OF THE BLIND

Senator **Harkin**. Next is Mr. R. Creig Slayton, director of the Iowa Department for the Blind, representing here on behalf of the Council of State Administrators of Vocational Rehabilitation.

Welcome to the subcommittee, and again, your statement is part of the record. If you would summarize it, I would be most appreciative.

Mr. **Slayton**. Certainly, Senator. It looks like constituent day. I am wondering who is minding the shop back in Iowa. [Laughter.]

It is certainly a pleasure for me to be able to be here representing the Council of State Administrators of Vocational Rehabilitation Services. We are the State partner in the Federal/State vocational rehabilitation program. I personally am pleased to be here because I received services as a vocational rehabilitation client and have long been an advocate of those services.

Today, here, I am here to really push for the Federal funding for basic support services for the vocational rehabilitation program. We are asking for the full authorization level in the act, which is $1,875,500,000. These are the basic—these funds provide the basic services in vocational rehabilitation.

This current year we will serve approximately 931,000 disabled individuals. We believe that the $1,875,500,000 in 1991—we can serve an additional 148,000 individuals. We have checked with the various State directors around the country, and we are confident that we can, in fact, match that much money and even more, and we will be able to effectively use it.

In addition to the basic support program, we would also like to see the supported employment program funded at $30.95 million. Independent Living, part A, at $14.43 million, Independent Living, part B, at $30.17 million, and part C at $6.56 million.

### PREPARED STATEMENT

As you well know, the Vocational Rehabilitation Program is not just another training program. We are a specialized delivery service providing specialized services with specially trained personnel. Disabled individuals in this country do not want a handout. We want a hand up. We believe that the Americans With Disability Act, coupled with adequate funding of the vocational rehabilitation program constitutes that hand up.

[The statement follows:]

# STATEMENT OF R. CREIG SLAYTON, DIRECTOR OF THE IOWA DEPARTMENT OF THE BLIND ON BEHALF OF THE COUNCIL OF STATE ADMINISTRATORS OF VOCATIONAL REHABILITATION

## COUNCIL OF STATE ADMINISTRATORS OF VOCATIONAL REHABILITATION

The Council of State Administrators of Vocational Rehabilitation is comprised of the chief administrators of the public agencies providing rehabilitation services to persons with disabilities in the fifty states, the District of Columbia, and the territories.

These agencies constitute the state partners in the State-Federal Program of Rehabilitation Services for persons with mental and/or physical disabilities, as authorized by the Rehabilitation Act of 1973, P.L. 93-112, as amended.

While the Rehabilitation Act is the cornerstone of our Nation's commitment to assisting eligible people with disabilities to obtain competitive employment, and to live independent and productive lives, it is severely underfunded.

When one considers that a Louis Harris and Associates study estimates that two out of every three adults with a disability are unemployed, and that the Rehabilitation Program has the resources to provide services to only one in twenty eligible people, it constitutes an unacceptable tragedy for the millions of people with disabilities who need services, yet are unable to receive them.

The great responsibility placed upon the Rehabilitation Program will become even more acute, when the Congress enacts the proposed "Americans with Disabilities Act (ADA)." The ADA will vastly expand opportunities for all Americans with disabilities. It is vital that the Rehabilitation Program be fully prepared to assist people with disabilities to fully realize the promise of this landmark legislation.

## VOCATIONAL REHABILITATION SERVICES; BASIC STATE GRANTS

### Section 110

| | |
|---|---|
| **FY 1991 CSAVR RECOMMENDATION..................** | **$1,875,512,100** |
| **FY 1991 AUTHORIZATION..........................** | **$1,875,512,100** |

Basic State Service Grants are the lifeblood of the Vocational Rehabilitation Program, financing the provision of vocational rehabilitation services to eligible individuals with mental and physical disabilities.

These Federal dollars, matched with state monies, permit State Rehabilitation Agencies to provide, or contract with private organizations and agencies to provide, individualized, comprehensive services to eligible persons with mental and/or physical disabilities, for the purpose of rendering these individuals employed and independent.

Such services may include evaluation; comprehensive diagnostic services; counseling; physical restoration; rehabilitation engineering; the provision of various kinds of training and training supplies, tools and equipment; prosthetic devices; placement; transportation; post-employment services; and any other service necessary to rehabilitate an individual into employment.

For Fiscal Year 1990, the Federal government estimates that the $1,528,500,000 appropriated for Basic State Vocational Rehabilitation will serve 931,000 people with disabilities, of whom an estimated 62.5 percent will be rehabilitated into employment.

Despite this expenditure, there still are not sufficient funds to serve all those eligible, disabled people who have the potential and desire to work and who need rehabilitation services to obtain employment and self-sufficiency.

Alarmingly enough, our best estimates are that State Rehabilitation Agencies are able to serve only one out of every twenty people who are eligible, due to a total lack of resources.

In FY 1988, 65.5 percent of all individuals served by State Rehabilitation Agencies were described as being "severely disabled" by the Federal Rehabilitation Services Administration.

In carrying out the mandate of the Act to give priority of service to the rehabilitation of individuals who are severely disabled, State Agencies have found that the costs -- in time, effort, and money for services -- are much greater than the cost of rehabilitating people less severely disabled -- greater by over 50 percent.

At the same time, it is alarming to note that the purchasing power of the Federal Rehabilitation Appropriation has remained virtually stagnant since 1980. According to the Congressional Research Service, it increased by only 1.8 percent from 1980 to 1988.

This means that the Program is serving fewer people, while expending more money for adequate services, adequately-trained staff, adequate equipment, and adequate facilities.

With these statistics in mind, the Council strongly urges that the Congress provide Federal appropriations for Basic State Vocational Rehabilitation Services in the amount of $1,875,512,100 for Fiscal Year 1991, the amount authorized in the law.

A recent CSAVR Survey of all State Rehabilitation Agencies found that with a Congressional appropriation of $1,875.5 million for FY 1991, an additional 148,000 people with disabilities will receive these vital rehabilitation services. The Survey also shows that the States clearly have the ability to match, and effectively use, these valuable service monies.

The justification for higher funding levels stems from the purpose for which the money is spent--the prevention of an incalculable waste of human potential--a purpose on which no price tag can be placed.

Appropriating additional monies for Vocational Rehabilitation Services reduces the Federal Deficit.

Over the decades, Vocational Rehabilitation has more than paid for itself by helping persons with disabilities increase their earning

**capacity; by freeing family members to work; and/or by decreasing the amount of welfare payments, health services, and social services they might need; as well as by assisting them to become taxpayers.**

The Congressional Budget Office has stated that "a reduction of funds for rehabilitation ... would generate increases in other parts of the federal and state budgets."

**Funds appropriated for Vocational Rehabilitation are a sound investment of the Public's money.**

OTHER PROGRAMS AUTHORIZED BY THE REHABILITATION ACT

The Rehabilitation Act is recognized as the most complete and well-balanced piece of legislation in the human services field. In addition to the Basic State Vocational Rehabilitation Services Program, the Act contains provisions for (1) an innovation and expansion program; (2) a training program; (3) a research program; (4) a comprehensive services for independent living program; (5) a supported employment program; and, among others, (6) special projects and demonstration efforts.

The CSAVR strongly supports adequate funding for all Sections of the Act, and wholeheartedly joins with the recommendations provided this Subcommittee by other Organizations and Advocates.

*Recommendations of the Council of State Administrators of Vocational Rehabilitation regarding fiscal year 1991 appropriations for programs authorized by the Rehabilitation Act, as amended*

| *Item* | *Millions* |
|---|---|
| Basic State vocational rehabilitation services—section 110 | $1,875.50 |
| State supported employment services—section 638 | 30.95 |
| Comprehensive State independent living services—part A, title VII | 14.43 |
| Centers for independent living—part B, title VII | 30.17 |
| Independent living services for older blind individuals—part C, title VII | 6.56 |
| Rehabilitation training—section 304(e) | 38.52 |
| National Institute on Disability and Rehabilitation Research—section 204 | 60.38 |
| Special demonstration projects several sections in title III | 31.36 |
| Projects with industry—section 621 | 19.93 |
| Client assistance programs—section 112 | 8.70 |
| Technology—State demonstration grants and national projects | 30.90 |

Senator HARKIN. Absolutely, I just want you to know, Mr. Slayton, I think the ADA, that we will get it passed this year and sign it. And along with the passage of that we are going to break down a lot of barriers to employment. And so we are going to need that kind of vocational training out there. We are going to need it out there to make sure that, even though we bring the barriers down, we have to also make sure that people are equipped with the right skills to take those jobs.

Mr. SLAYTON. Just absolutely essential. We believe this is going to increase very substantially, the number of persons who will suddenly believe that it is possible for them to get a job, that it is possible for them to play a full role in the community and actually first-class citizenship.

Senator HARKIN. Nothing less will do, and I just want you to know, last year I was proud. I worked hard on this. We got $100 million increase last year, over 1989 in 1990. So we will keep on that track. Thank you very much.

## STATEMENT OF STEPHEN BLAIR, PRESIDENT, NATIONAL ASSOCIATION OF TRADE AND TECHNICAL SCHOOLS

### ACCOMPANIED BY NANCY O'BRIEN

Senator HARKIN. Next is Stephen Blair, president of the National Association of Trade and Technical Schools.

Mr. Blair, welcome again to the subcommittee. It is good to see you again.

Mr. BLAIR. I would like to introduce Nancy O'Brien, who I know you have met before. She will help me if we get into the details.

Senator HARKIN. I brought my brains with me today, too.

Mr. BLAIR. Mr. Chairman, I am Stephen Blair, president of the National Association of Trade and Technical Schools, which is composed of some 640,000 students attending some 1,200 private trade schools.

Each year private, postsecondary trade and technical schools produce one-half of our Nation's skilled people who are entering the work force for the first time. These schools are also a major source of opportunity for millions of Americans who need technical education in order to meet the demands of the changing workplace.

It is estimated that during this decade only 20 percent of the jobs in this Nation will require a college degree, but 80 percent will require some form of education beyond high school, particularly technical education.

Educational opportunities will be seriously diminished if Congress fails to provide the additional requested $5 billion above current funding, and also fails to reduce the imbalance between the student financial aid loan and grants. In 1980, grants constituted 40 percent of the typical aid package, with loans providing the remainder. Now, grants comprise only 29 percent of the typical aid package. Coupled with other changes in student aid, people find it increasingly difficult to pay for postsecondary education.

Some perceive that the growing number of trade school students receiving financial aid is a threat to the student aid system, yet they fail to see it truly as the reflection of the growing demand for career-specific education. Over the past 5 years, Motorola alone has hired 100 technicians from the Hamilton Technical College in Iowa, the school that you had the opportunity to visit. Lockheed has hired 350 graduates from the Pittsburgh Institute of Aeronautics for its Georgia plant. Our graduates can adapt to new technology and have a solid background to advance in their fields.

Private career schools have a higher completion rate than any other sector, and yet, because our schools have in service, significantly higher portion of high-risk students, our default rates tend to be higher. Almost 3 years ago, private career schools launched a major default management initiative and are currently conducting a third in a series of workshops to reduce defaults even further. As a result of the initiative, trade schools posted the largest decrease in student loan defaults compared to any other sector. We are confident that private career school rates will continue to decline. Our concern is that further reductions may be because private career schools are withdrawing from serving the high-risk students, simply in order to meet an acceptable default rate.

### PREPARED STATEMENT

We are also committed to ensuring public confidence in accreditation and accredited schools. As such, we are about to introduce major new reforms. We are successful at educating people. As you consider the funding levels for student financial aid programs in fiscal year 1991, please remember the needs of the nontraditional students, who will make up an ever increasing percentage of the work force.

Expanded support for all postsecondary students through Federal student aid is a cost-effective way of nurturing the human capital America needs to remain competitive in the global economy.

Thank you for your attention.

[The statement follows:]

# STATEMENT OF STEPHEN BLAIR, PRESIDENT, NATIONAL ASSOCIATION OF TRADE AND TECHNICAL SCHOOLS

Mr. Chairman, Members of the Subcommittee: My name is Stephen Blair. I am the President of the National Association of Trade and Technical Schools, which represents 1271 private postsecondary institutions. I am pleased to have this opportunity to testify today on the federal funding needs for postsecondary education.

Trade and technical schools are the primary suppliers of skilled workers for American business and industry. They produce half the skilled, entry-level workers in our nation today, from the artisan who makes a Stradivarius sing again, to the technician who keeps our airplanes flying safely. More importantly, trade and technical schools are a major source of career opportunities for millions of Americans who need technical education to meet the demands of American business and industry's changing workplace.

This important sector of postsecondary education is proud of its work to help prepare America's skilled artisans, craftspeople, and technicians. However, that work will be seriously damaged if the Congress does not remedy funding losses incurred under the Gramm-Rudman sequestration in Fiscal Year 1990. Those cuts will eliminate Pell Grants for 14,000 students, and reduce grant awards for 1.3 million students for the 1990-91 academic year. President Bush does not support restoring these losses. Further, the President's budget proposal for Fiscal Year 1991 would bring additional cuts in real dollars for the 1991-92 academic award year. Current funding allows for only a $2300 maximum Pell grant, a decrease of 17 percent in constant dollars since 1980. The President does not propose increasing this amount.

Why should Congress ensure full Pell Grant funding? Every headline and blue ribbon panel says society must help all Americans become productive workers. The needs of the labor market will require that virtually every worker be skilled, but short-sighted cuts in Pell Grants make it more difficult for workers to get the technical education they need. More than ever, we need to bolster support for career-specific postsecondary education. It is estimated that over the next decade, 80 percent of all jobs will not require a college degree, but will require some degree of postsecondary education. Federal, state, and local governments and private entities spend $45 billion a year subsidizing college students and barely $7 billion a year on postsecondary education for non-college bound youth.

Congress also must reduce the brutal imbalance between loans and grants that has forced our neediest students to rely upon loans to finance their postsecondary education. In 1980, grants constituted 40 percent of the typical aid package, with loans making up most of the remainder. Now, grants comprise only 29 percent of the typical package. Coupled with other changes in student aid, such as a cap on borrowing under the Stafford Student Loan program and restrictions on Supplemental Loans for Students (SLS), people are increasingly hard-pressed to pay for the education required for most good jobs now available. This means the students who graduate from postsecondary trade and technical schools embark on their career path carrying a crushing debt burden.

The growing percentage of trade and technical school students who benefit from financial aid should not be perceived as a threat to the student aid system, but as a reflection of the increasing demand for this type of education. According to the Department of Education, the number of bachelor degrees granted between 1972 and 1985 increased by 7.1 percent, while the number of associate degrees increased by 41 percent. This does not include the explosive growth in certificate programs. Pell Grants and the Guaranteed Student Loan programs help trade and technical students, many of whom live independently from their parents, to offset their high level of financial need.

Let me tell you about some of our graduates, if I may.

Dale Corrice, 45, a trunk and communications technician at Motorola, had been employed as a grocery store stock boy for 10 years, before he graduated from Hamilton Technical College this year. He credits Hamilton Tech with giving him the opportunity to achieve his version of the American dream. Motorola has hired over 100 technicians from Hamilton Tech in the past five years.

Frank Fanto, director of production operations for Lockheed, credits his education at the Pittsburgh Institute of Aeronautics (PIA) for "laying the foundation for entering the aircraft industry." Under his influence, Lockheed has hired 350 PIA graduates at its Georgia plant.

Our graduates, like Frank Fanto and Dale Corrice, are productive members of society. Many are single mothers who need technical skills to improve their lives. With the changing needs of the workforce, and the large number of people who do not choose to attend traditional colleges, trade and technical schools are playing an increasingly important role in developing the labor pool this nation must have to remain competitive with a united Europe and a financially powerful Asia. Without further education, the capabilities of America's non-college bound students will never develop to their full potential.

Today, business leaders are clamoring for more highly skilled workers. Three-fourths of all new jobs created during the 1990s will require some form of postsecondary education. Moreover, by the year 2000, a large portion of new job opportunities will be in companies with fewer than 100 employees. Yet, these companies are the least able to provide remediation and technical education.

It is no wonder, then, that some of the strongest supporters of trade and technical schools are business people. They hire 81 percent of our graduates to perform work in their chosen fields immediately upon graduation. Contrary to popular belief, these students are not stuck in entry-level jobs, but have the solid background to advance in their fields and can adapt to new technology. Indeed, 18 of the 20 fastest growing occupations are taught in postsecondary trade and technical schools.

Our schools are not perfect. Some trade schools have abused the student aid system. We are working with the Department of Education and the Congress to curb these abuses. NATTS fully supported the provision which was included in the Omnibus Budget Reconciliation Act of 1989 that prohibits loans to students attending schools which have withdrawn under suspicion from an accrediting body whose accreditation has been revoked.

While these abuses are a serious concern, it is important to note that they are not the root of the default problem. All research demonstrates that the default rate of a postsecondary institution, lender, or guarantee agency is primarily a function of the population served. In addition, the cost of educating "at-risk" students, and making and administering loans for them, are greater regardless of the type of postsecondary institution the students attend.

Because trade and technical schools serve a significantly higher proportion of low-income women, minorities, and at-risk students than any other postsecondary sector, our default rates tend to be higher. In spite of this high-risk population, trade and technical schools are successful. More than 60 percent of our students complete their education compared to 43 percent in public community colleges, 58 percent in four-year colleges, and 33 percent in the Job Corps.

While NATTS schools have higher completion rates than other sectors, we are continually striving to improve in many ways. With regard to defaults, we launched a major Default Reduction Initiative three years ago in conjunction with other groups in the proprietary sector. We are currently conducting a second series of workshops for this initiative which include an emphasis on "life skills." The results of this effort are already evident. The Secretary of Education recently reported that trade schools posted the largest decrease in loan defaults of any sector of postsecondary education from Fiscal Year 1986 to Fiscal Year 1987. We anticipate further reductions when the Fiscal Year 1988 default rates are reported.

We are committed to ensuring public confidence in accreditation and accredited schools. We are introducing new reforms in several areas, including ability-to-benefit testing. The American Council on Education is currently developing admissions tests for NATTS schools nationwide. Students who do not meet cut-off scores could be denied admission and all degree program students may soon be required to earn a GED prior to graduation. This is just one example of the reforms under consideration, and NATTS is taking a strong stand to improve postsecondary education across this great nation.

In conclusion, I would like to stress that we are committed to providing quality education and opportunities for the population that needs most to be brought into society's mainstream. At a time when the nation has a shortage of skilled workers, we are educating people for satisfying and important careers. We are successful at what we do, and no sector in postsecondary education is more accountable or more committed to students. At the same time, we know we can do more and we are proposing new reforms to ensure that all trade and technical schools are the best they can be.

As you consider funding levels for student aid programs for Fiscal Year 1991, please keep in mind the needs of the workforce and non-traditional students. Increased funding for federal student aid programs is the most important step you can take in addressing these needs. Continued, and even expanded, support for our students through student aid programs is a cost-effective way of nurturing the labor force America needs to remain competitive in the global economy.

Thank you very much for you attention.

Senator HARKIN. Thank you very much, Mr. Blair. It is not often that we get a representative of an organization here that says some members of that organization have abused the system, and your statement here that our schools are not perfect, some trade schools have abused the student aid system, I think—I appreciate your forthrightness.

But the trade and technical schools do a great job in this country and prepare a lot of low-income people, who, otherwise, would be relegated to a lifetime of meager income, minimum wage or below jobs, who now will have some kind of a skill that will allow them to make an income to feed and clothe the family, be a homemaker and a taxpayer in this country.

The abuses, the problems we have, we can get over those things. We can work those things out in a way to make sure that we continue a strong trade and technical school system in this country. I am committed to that, and I know you are too. And I know your organization is. We have worked together on this, and I look forward to working with you in the future.

Mr. BLAIR. Thank you.

### STATEMENT OF JUNE LEFFLER, NATIONAL CAPTIONING INSTITUTE

Senator HARKIN. Ms. Leffler, welcome, and again, make your statement for the record. Please proceed.

Ms. LEFFLER. Good morning, Senator. It is such a privilege for me to be here today to testify on behalf of the National Captioning Institute, but also on behalf of my children, also as an advocate for placement of decoders to needy children in the United States still not using this wonderful technology.

I am happy to tell you that the Captioning Institute is celebrating their 10th anniversary—that is 10 years, and this is your celebration as well.

Senator HARKIN. I remember when you started. I was working on the House side at the time, and Jennings Randolph on the Senate side, back in the 1970's, to get the thing going, and I was at the White House when the first decoder was presented in the White House to then President Carter, and was down with Jennings Randolph.

Ms. LEFFLER. That was 10 years ago, and believe me 10 years ago as a parent we were struggling with deafness, and I remember the boys getting their first decoder and looking at their faces all I could say at that point was, what a wonderful country. I wanted to tell the people in Washington. I could not believe somebody was sensitive and really caring about my children and our home.

I would also like to announce today that Nevada on March 19 is also celebrating, because they are the first State in the country after a project that was coordinated with the National Captioning Institute to be the model State for close captioned television. Every deaf child in the State has a decoder in their home. Every school district has a decoder in their research center.

Senator HARKIN. Who bought the decoder?

Ms. LEFFLER. They were provided by the State of Nevada, by the Lions Club, by the First Interstate Bank of Nevada, the Mining Association of Nevada and Harris Hotels and Casinos, and it is not just the children, units were put in the curriculum development department, because now that these kids have this access to information they are going to definitely have to update what these kids are learning in the classroom because they are far more aware.

Senator HARKIN. This is a new decoder. That is smaller than the old one.

Ms. LEFFLER. They have come so far in programming, but this is a smaller decoder and it goes anywhere.

Senator HARKIN. How much does that cost?

Ms. LEFFLER. This decoder is approximately $170.

Senator HARKIN. It is cheaper than the original ones.

Ms. LEFFLER. You bet, and it goes to Grandma's house, and it goes to the university where my son goes, and it is real important that they are never denied television information.

But I want to get back to Nevada, because it is not just the children. Decoders were put in every nursing home, every hospital, State-operated hospital. They are in all the libraries and have been used in the illiteracy programs and also for adult education, and again that is a first, and we are going to see more States coming up this year.

Now, 10 years ago Andy would watch a program on a Monday and he would have to wait until Friday for another program that was for children. I went to Gallaudet University last night and I said Andrew, if you were here today what would you tell the Senate? He simply said, there has been such a growth in television programming. I used to come home and pick up the newspaper to see what was captioned. He said, now I do not bother. I go to the television and turn it on, because all of prime time programming is closed captioned.

Our young Brian came home after school, threw down his books, and they had the American Music Awards and he flipped on the block and he goes, my favorite song. I never knew he used the words, but there are captioned music videos. They were the first ones to pay $7 a ticket to watch Batman, but you can bet they were the first ones to go into the video store when the captioned release came out, but then they came back because it is real hard to lip read the Joker, and they understood what was happening.

So we are talking about what happened in Nevada, my children, but my project with the National Captioning Institute is probably 80 percent of the children in this country after 10 years do not get vital decoder equipment, and you cannot be in the classroom or learning about your neighborhoods through local news and what is happening in this ever-changing world without the equipment.

I am also—in the testimony there is a request for subsidy funds to meet the needs of these children. One letter from a little boy that got a decoder in a program in the Bronx was so unique, because it simply said—and it was by his teacher, actually—communication is not just learning signs and learning speech as a child, it is having something to talk about.

## PREPARED STATEMENT

There was a little, very shy boy, and he went into school and would never really cooperate in expressive language. Two weeks after he got his decoder, he comes and he talks to the janitors, he talks to the ladies in the cafeteria, he talks about the weather. He has something to talk about. I think all of the children in our country, after 10 years of knowing that this is around, deserve that same benefit.

I thank you for letting me testify today.

[The statement follows:]

## STATEMENT OF JUNE LEFFLER, NATIONAL CAPTIONING INSTITUTE

The National Captioning Institute (NCI) appreciates this opportunity to submit testimony in support of the FY 1991 budget needs of the Media Services and Adaptation Branch of the U.S. Department of Education. NCI is a Section 501 (c) (3) nonprofit organization now celebrating the ten year anniversary of its inauguration of closed captioning television services which have benefited millions of American citizens who are deaf and hard-of-hearing. Although private sector support now provides more than half of all TV captioning, federal appropriated funds are vital to continue captioning and decoder services at present levels.

For FY 1991, NCI recommends the following appropriations:

| | |
|---|---|
| Captioning of local and national TV news, children's, educational, and other programs— | $6.5 million |
| Providing decoders to 7,500 deaf children currently without them— | $1.0 million |
| Public Awareness and Education — | $1.0 million |
| Research and Technology Development— | $1.5 million |
| TOTAL | $ 10 million |

## BACKGROUND

In 1988, the Commission on Education of the Deaf reported that captioned television is a vital aspect of the daily lives of hearing-impaired Americans, should be expanded to include all television programming, and be available to all hearing-handicapped citizens. Inherent in the Commission's report and its recommendations was the need for a greater federal role in establishing an affirmative action plan that would lead to more widespread captioning of broadcast and cablecast TV programs, as well as those video materials produced with federal funds, including those presented in public places.

It is worthy of note that both the House of Representatives and the Senate have modified their rules to allow captioning of its televised proceedings. NCI has obtained the cooperation of C-Span in planning for future captioning, and hopefully, these events will rapidly lead to accessibility of these proceedings by the hearing-impaired community.

## CURRENT SERVICES

The number of hours of closed-captioned programming available on broadcast TV, cable TV, and home video has increased dramatically in the last year. These increases have resulted in large part from increased funding from the Department of Education, which has had a multiplying effect on matched funding from the private sector. Department of Education initiatives are also partially responsible for the increased diversity of captioned programs available to hearing-impaired Americans. For example, one initiative provides funding for captioning of all major sporting events televised by the networks and basic cable systems; a second initiative provided funding for the captioning of prime time movies, mini-series, specials and, for the first time, daytime dramas. Elderly hearing-impaired persons who are home during the day are now able to enjoy a significant amount of daytime television.

These federally-funded captioned programs are joined by a variety of syndicated shows which continue to be captioned with full private sector support. NCI has also secured private sector funding to caption such special events as the Olympic Games. NCI's Cable Captioning Consortium involves seven leading basic cable networks and fifteen of the top cable Multiple System Operators. Launched in 1988, the Consortium has made possible the captioning of hundreds of hours of programming on basic cable, ranging from sports and drama to music and cartoons.

All three major commercial television networks and the Public Broadcasting Service continue their commitment of supporting captioning costs. As a result, 100% of all prime time (evening) programming on the commercial networks is now captioned, a significant increase over the 66% of just three years ago. In addition, most PBS adult and children's programs are captioned.

Captioned news and public affairs programming on the networks has increased over the past several years, through a combination of federal and network funding. Other funding from DOED enables NCI to caption many children's TV programs, including SESAME STREET, MR. ROGERS' NEIGHBORHOOD, and many other PBS, commercial network, basic cable, and syndicated programs.

However, despite these promising notes, on-going federal support of the captioning service is needed to assure that the captioning service maintains its current level of service to hearing-impaired citizens. The program areas that are funded by the Department of Education are not attractive to potential private sector captioning funders. It is only through the government's continued investment in the captioning service that the audience for captioning will continue to grow, and deaf and hard-of-hearing persons will continue to be mainstreamed into the most vital of America's mass communications medium.

## REMAINING NEEDS

The Commission on Education of the Deaf also stressed the need for the availability of televisions with caption decoding circuitry built in by the TV set manufacturer. In response to the Commission's recommendation, NCI has embarked upon an exciting technical development effort that will produce a low-cost, single chip decoding capability. This chip will be made available to television manufacturers by the end of 1990 for about $5. This will enable new TV sets with built-in decoding capability to be available by 1992. NCI is pleased to report that this development activity is fully funded and well within schedule. The promise of this breakthrough is clear — widespread availability of the captioning service at nominal cost to the consumer.

There continues to be a need to provide low-cost decoders to hearing-impaired persons who may not have the means to purchase a decoder or a new television set. In the past, Congress has supported funding for decoder subsidy programs to ensure that decoders remain affordable for those who need them. NCI once again urges federal support for this vital program that will assist in bringing the captioning technology to a population that could most benefit from its availability — hearing-impaired children.

The Commission on Education of the Deaf reported that there were 36,000 deaf students in the United States in 1985-86. It has been reported that 80% of these young people still do not have access to a decoder. A priority should be placed on developing and implementing a plan that would provide decoders to this group over a several year period. At a subsidy funding level of $1 million, decoders could be distributed to hearing-impaired learners under a long-term loan program managed through schools and other means. At the recommended funding level, every hearing-impaired student would receive a decoder within a four-year period. After that, the incremental cost of maintaining the program for new students entering school programs would be minimal. This program would help bring captioned television in to the homes of hearing-impaired youth, providing them with the "Reading Machine" that is vital to their successful acquisition of language.

> *"Our son, Timothy, age 7 years, is severely hearing impaired. He attends a deaf education school here in Pinellas County. Today he received a caption decoder as a gift from the a local Lions Club. We had been planning to purchase one, but unexpected doctor bills and other expenses related to hearing aids had taken any extra money, so it was with grateful hearts that we received this.*
>
> *Our heartfelt appreciation to you for helping our son in his continued learning to adjust to living in a world that seems to know so little about the difficulties of being hearing impaired, as Timmy is, just learning to read."*
>
> Jerry and Virginia T.
> St. Petersburg, Florida

Other activities recommended for funding in FY 1991 are as follows:

Public Awareness and Public Education

NCI urges that a more aggressive program be initiated with federal support to ensure that the many persons in the United States who could benefit from the captioning service are made aware of the availability of captioned TV programs and the decoder device. Among the populations which should be targeted are the elderly, as well as persons with reading and learning problems, and persons learning English as a second language. The captioning service has been found to be a valuable learning tool for these large groups.

Ongoing Research

Over the past ten years, NCI has initiated several research studies into the effectiveness of captioned television as an educational tool. NCI believes that federal support for wide-ranging additional research into caption readability and the measurement of its effect on the acquisition of reading skills is desirable and necessary. With the audience for the captioning service steadily increasing, and the availability of increased captioned programming for children, additional research should be undertaken that will lead to improved captioning standards and techniques.

Technology

As NCI continues to improve captioning technology, it is also monitoring the development of High Definition Television (HDTV). federal support of on-going investigation of various systems being proposed as the new transmission and reception standards in this country will assist in assuring that captioning be made an integral part of the development of any new technological advancement. Other areas of development which should be investigated include the use of infra-red technology to assist hard-of-hearing persons in their understanding of television.

## FUNDING RECOMMENDATIONS

It is vital that currently funded captioned programming initiatives continue, thus allowing deaf and hard-of-hearing Americans access to these important segments of televised education, information, and entertainment. Continued federal support should also be used to leverage the private sector to steadily increase its commitment to captioning. **Specific captioning program funding levels recommended for FY 1991 are as follows:**

**National News — $2.2 million**
**Children's Programming — $1 million**
**Syndicated Programming — $0.8 million**
**Sports Programming — $0.5 million**
**Prime Time & Daytime — $1 million**
**Local News — $1 million**
**TOTAL $6.5 million**

This recommended funding level for captioned programming would allow for a modest increase in support for the vital area of captioned national news programming, as well as an increase in start-up funds to initiate captioning of local news programming. This latter funding assistance will encourage local TV stations to investigate and implement new technologies such as electronic newsroom captioning that can provide captioning services at little or no on-going cost to the TV station. NCI believes that with a sustained effort, this initiative would lead to captioning of local news programs in virtually every TV market within a few years.

**NCI recommends a $1 million funding level of a decoder subsidy program specifically targeted to deaf and hard-of-hearing school age children.**

**An aggressive public awareness and public education initiative designed to reach those potential audiences that are as yet untapped beneficiaries of the captioning service should be funded at the $1 million level. On-going research into caption readability and the effect of captioning on reading and development of technologies that will further the mainstreaming of our hearing-impaired citizens into society, including HDTV, should be funded at the $1.5 million level.**

NCI recognizes that the economic times we are living in require moderation in the hopes and aspirations placed on federal resources. Therefore, these FY 1991 recommended levels approximate the appropriated levels for these activities during FY 1990.

NCI believes the above are critical funding areas that fit the leadership role that Congress has played in the development and growth of the closed captioned television service.NCI wishes to express its sincere appreciation for the confidence that Congress and the Department of Education have shown in giving NCI such a crucial role to play in the development of so vital a service for so many previously ignored hearing-impaired persons.

Thank you for this opportunity to submit this testimony.

Senator HARKIN. We thank you for being here. I remember when my brother got his first decoder. It was quite a thing, to watch movies on television and Billy understand what was going on. I remember when we got our first television set. He had been watching us always listening to the radio, and back in the 1950's when we had our first television set, man, that was something. Then when you get the decoder, that was really something.

Ms. LEFFLER. It is important, and we have a hearing son, too, my Steven, he deserves a break of always saying what is happening, and interpreting, and when there is two deaf and one hearing, he deserves to watch a program he likes as well.

Senator **Harkin**. You know, I have a bill to put chips in all the television sets, and I think we are going to get that through now. So hopefully in a few years—I was just talking about we are going to develop a chip, they know they can do it, that goes in every television, and every television set will have it in, and my bills calls for every television set over 13 inches to have it in.

Ms. **Leffler**. I thank you for sponsoring that bill, but I want to stress that this money is desperately needed now, because you cannot recapture missed television information, especially as a student, and it is going to be—those that we are helping are definitely minority children, children with a lot of financial need. Their parents, if they cannot afford this they basically will not go out and buy a television set, but I am looking to the future where no matter what hotel, hospital they go in, television will have the capability.

Senator **Harkin**. How heavy is that?

Ms. **Leffler**. It is about 4 pounds.

Senator **Harkin**. Is Sears marketing these?

Ms. **Leffler**. Sears, Highland, Penny's—there are many different sources where you can now buy it.

Senator **Harkin**. But it is basically—well, yes, the National Captioning Institute.

Ms. **Leffler**. It is much easier to hook up. It is simply two jacks and is compatible with any television, the VCR and also your cable service, which is important. So we are very thrilled.

Senator **Harkin**. What did you say, $180?

Ms. **Leffler**. Approximately $170, $180 with shipping.

Senator **Harkin**. Thank you for being here.

### STATEMENT OF DAVID J. BRUGGER, NATIONAL ASSOCIATION OF PUBLIC TELEVISION STATIONS

Senator **Harkin**. Next is David Brugger, representing the National Association of Public Television Stations.

Mr. **Brugger**. Thank you, Mr. Chairman. I feel at home today, since I was in Iowa for 10 years. That is where I started in public broadcasting as we helped build the State network out there, 1967 to 1977.

Senator **Harkin**. Well, it is doing well. It is one of the best in the country, and in fact as you know in Iowa we are doing fiberoptics now.

Mr. **Brugger**. I am aware of that project. It is great to be on the forefront of technology.

I am talking to you today about solutions, and public television is addressing a lot of the solutions that you talk about here this morning, and just picking up on some of the testimony, there was Senator Simon talking about illiteracy. Public television has been involved in the last 4 years in the U.S. literacy efforts, and we have now 425 task forces around the country established to work on the literacy problem.

You have talked about the captioning for the hearing impaired, and as you know the original technology for that was developed by PBS before they established the National Captioning Institute. We are certainly supportive of putting a chip in every one of the television sets, and you know almost all of our programming now is captioned also.

We even have descriptive services for the blind, now, and there are 32 stations who are pioneering this service and we are hoping that with the appropriate funding we can get that to all of the stations, too, so that they now can enjoy television more and education in general, you may know that we are serving about 29 million students across the country including rural States like North Dakota where they have 59,000 students who are getting instructional television.

We have always appreciated your support and the support of this committee, and we are asking you to renew that commitment to us this year. Specifically, we want fully authorized funding for the Corporation for Public Broadcasting. If we leverage seven non-Federal dollars for every $1 that we get from the Federal Government to provide a lot of the local services out there, then we think that is a good cost-effective investment for the Federal Government.

We are especially concerned about getting the third and final payment on the satellite replacement for the existing system. If our stations are going to have the ground equipment that they are going to need to be able to take advantage of the new technology, especially the distance learning projects that are brought about by Star School and so on, it is going to be important that we have the money to equip those ground stations so they can receive that kind of programming.

The Department of Education; we want continued funding for the Star Schools, for descriptive video and captioning, the Secretary's fund for innovation. They make possible the new math and science series that were helping children get their cognitive powers honed.

I guess there is a final comment. I think you understand the importance of media in this society and the role it plays—just look what it did in Eastern Europe—and the vital role that it plays in this country. We are the only service whose bottom line is public service, not the profit ratio, and we think that is a pretty important investment. We have to maintain the public service lines of communication to all of the needs that you are concerned about and that a lot of other people are concerned about, and I want to thank you for your support.

### PREPARED STATEMENT

If I could add one personal note, this is not part of the official testimony, but I found out 9 months ago I have tinnitus, and I learned a lot this morning just being here at the hearing myself, and I hope that there is some research even if it is not going to help me.

[The statement follows:]

# STATEMENT OF DAVID J. BRUGGER, NATIONAL ASSOCIATION OF PUBLIC TELEVISION STATIONS

## Public Television: Part of the Solution

**Mr. Chairman, public television means solutions.** What you see on your screen at night is only one aspect of a wide variety of services provided by public television stations. Many of the problems your subcommittee deals with are being addressed by public television.

Every dollar this subcommittee appropriates toward the fully-authorized amount for public television is a dollar invested cost-effectively in helping your constituents solve problems at the national and local level. Specific examples are listed below.

We appreciate the support from Congress and this subcommittee over the years. The percentage of our total budgets provided by federal funds has declined to 17 percent. With additional support, our stations could build on their track records of community service and do so much more.

## Public Television's Specific Appropriations Request

- On behalf of the nation's public TV stations **we urge this subcommittee to fund the Corporation for Public Broadcasting at the fully-authorized level of $285 million for FY 1993** to ensure continued support for national programming and community service grants to stations.

- **We request a final appropriation of $66.94 million to complete the satellite interconnection replacement project.** Any amounts less than full funding of the satellite replacement will directly reduce the capacity on the ground which the stations must have to utilize satellite-delivered services. It will divide stations into the haves and the have-nots for services like distance learning, which are the future of public telecommunications.

- NAPTS also recommends continued significant funding for the Department of Education's Star Schools program for which $100 million was authorized for FY 1988-92. A total of $49 million remains authorized for FY 1991 and 1992. For this fiscal year, **NAPTS supports an appropriation of $25 million to the Star Schools Program** to allow for continued use of education technologies to make advanced math, science and foreign language instruction available to students who might otherwise be deprived.

- Public television stations also request funding for the Descriptive Video Services (DVS) program, a project from the WGBH, Boston, Education Foundation that makes television programs accessible for the blind and visually impaired. With your assistance public television can make its excellent dramatic programs, such as *American Playhouse*, *Masterpiece Theatre*, *WonderWorks* and *Mystery!* accessible to the more than five million visually impaired persons in the United States. **NAPTS recommends that $1 million be appropriated to the Department of Education for the Descriptive Video Service.**

- **We also request continued support for the closed captioning of television programs for the hearing impaired through the Department of Education.** Now a decade after public television led the development of closed-captioning, the application of the technology continues to grow rapidly with the majority of primetime television programs closed captioned.

Captioning is more than an enhancement for television entertainment and it benefits more than the hearing-impaired community. Studies during the past two years credit captioned children's programs — notably *Sesame Street* — as being an aid in the fight against illiteracy. Captioning also has been credited as an aid to those learning English as a second language.

- Finally, NAPTS supports the Secretary's Fund for Innovative Education, which in its first year provided $1.25 million for production of new *Square One TV* programs. **We support an appropriation of at least $8 million in 1991** for this fund to meet some of the major new education challenges for which public television can provide assistance.

## Public Television Stations Serve Their Communities

Public television stations were organized locally to better education. The federal government invested wisely in forging a national asset from local institutions, equipping them to address national concerns with the best programming that the nation could develop, delivered with sensitivity to local conditions.

Public stations have a long track record of participating with others in advancing common solutions through broadcasting. In joining the community of action, stations more and more are using the communications tools beyond traditional broadcast. The community involvement of public television is not new, but what is new is that the need has never been greater, as the influence of other institutions — very much including the family — has diminished in so many places.

Public television stations have mounted major community outreach campaigns on issues of national and local importance. Project Literacy U.S. (PLUS) involved more than 360 community and state task forces in literacy training and mentoring to address the problems of the more than 26 million adult illiterates in the US.

This year, public television stations across the country have joined together in OPERATION EARTH, with 35 hours of new primetime programming and a focus on environmental topics throughout the year in the major national program series.

National attention to other problems such as childcare, drug and alcohol abuse, teenage dropouts and AIDS, has been focused by public television stations working with community organizations and national social services organizations.

## Public Television is a Critical Education Instrument

Almost everyone is aware of *Sesame Street*, the landmark public television program that has demonstrated that television can be a powerful force in educating the young. Public television every day offers similar programs for older children that teach reading and mathematics.

In communities across the nation, public TV stations provide a daily average of five hours of quality educational material to some 1.5 million classrooms, which is available to 29 million school children. In addition, PBS adult learning telecourses are now used by three out of five US colleges and universities. Since their start in 1981 these telecourses have enabled a million Americans to earn college credits.

This valuable supplement to individual classroom instruction makes more sense than ever today, in a time when there is general agreement that the quality of education needs improvement and when teacher shortages, high teacher-student ratios and tight school board budgets prevail almost everywhere.

To cite just one example: GED courses on public television enable thousands of dropouts to earn high school diplomas. And the courses reach students everywhere, even in prisons and the armed forces.

Education through public television means video programming distributed by tape, interactive computer programs and databases; it means audio tapes, books and print instructional material of various kinds — in short, whatever it takes to make the job of teaching complete.

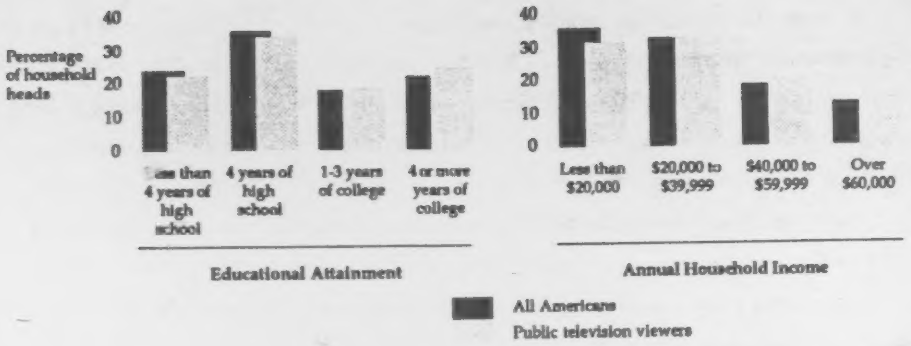
Further, the advance of technology makes it almost certain that television will play an even greater role in education in the future than it does today. The same technology that brought public television more actively into the classroom also makes it possible for public TV to play an exciting new role in workplace education, where the need is great and the costs today exceedingly high.

Currently, American business spends over $40 billion a year to educate some eight million of its workers. It's estimated that by the end of the century 75 percent of all workers will require re-training to remain productive.

Public television can help get this job done at costs greatly below current levels. For example, last year the cost of elementary and secondary education in the US totaled over $196 billion, or $4,550 per pupil. For a $1 million investment, an instructional television series employing the very best teachers can reach 4.5 million children in two grade levels for five years at an annual cost per pupil of four cents.

## Public Television Serves All Americans

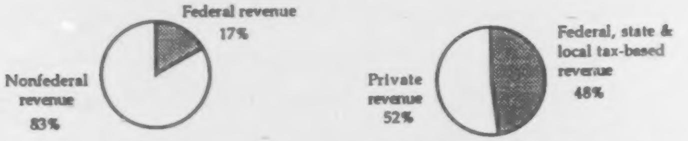
Public television is a medium that exists to provide a choice. This is the choice of some 87 million Americans each week. Public television is watched by welfare mothers and bank presidents, by stock brokers and stock clerks, by farm hands and factory owners, by dock workers and doctors — people from all walks of life. And, by the children of the underprivileged as well as privileged.



PUBLIC TELEVISION AUDIENCES REPRESENT AMERICANS OF ALL EDUCATIONAL AND INCOME LEVELS.

Public Television Provides a Strong Return on Investment

The federal investment in public television has been extremely cost effective. It has interconnected locally-supported public stations and has been used by stations to leverage five times as much funding from a variety of sources. Your investment allows stations to produce and acquire programs of more than local interest that would otherwise be beyond their means.



EACH FEDERAL DOLLAR IS MATCHED BY FIVE DOLLARS FROM OTHER SOURCES.

Public television is available in 98 percent of all American homes and in an average week over half of the nation's households tune in to it. Millions of Americans contribute additional funds to public television stations, representing 21 percent of total industry income. Every week 15 million children draw part of the benefit by watching our children's programs.

While we understand the realities of the federal budget, we feel that it is important to state the opportunities for public television to serve the nation with adequate federal funding. An investment in public television is an investment in the educational and social well-being of our country. We hope that this subcommittee and this Congress will recognize the value of the investment in public television and make a commitment to its increasing role in achieving the public policy objectives originally hoped for from this medium.

The recent spectacular events in eastern Europe and elsewhere have underscored the incredibly important role of the media in society. Public television offers a voice for those groups too small or too specialized to have their needs cared for by mass media. We believe it is a powerful medium for preserving and extending our democracy. The appropriation we are requesting is a very small investment to ensure that the voices of all Americans can be heard.

Senator HARKIN. I find more and more people that I talk to are afflicted at one level or another by it.

While we have always had a strong support here—I have been a strong supporter of public television—and we will see what we can do; 285 is the full authorization. Just quickly, if you were to get that, how would it best be utilized by the corporation?

Mr. BRUGGER. In getting that money out in the community service grants to the stations, because they then use that as leverage to out and match that money, and as I say we are getting a 7-to-1 ratio, and so it is a good incentive to get corporations and private citizens in. It is the tax-base funding that helps us do the kinds of services that you cannot really raise.

It is hard when you talk about descriptive video and a lot of the educational services. If the tax-based funding does not pay for it, it is hard to get corporations to do it or people to pledge on a fund drive on the air to those kinds of services, and that is where the tax-based funding is really helpful.

Senator HARKIN. We will do what we can. Thanks very much.

## STATEMENT OF STEPHEN S. BARRETT, DIRECTOR, HELEN KELLER NATIONAL CENTER FOR DEAF-BLIND YOUTHS AND ADULTS

## ACCOMPANIED BY VALERIE DWORK, MEMBER, BOARD OF TRUSTEES

Senator HARKIN. Next is Stephen Barrett, Director of the Helen Keller National Center for Deaf-Blind Youths and Adults.

Mr. BARRETT. Mr. Chairman, we appreciate the opportunity to appear before you today and to present testimony on the vital services needed by one of America's most severely disabled and multihandicapped populations, those individuals who are both deaf and blind.

My name is Stephen Barrett, I am the director of the Helen Keller National Center for Deaf-Blind Youths and Adults. We have previously submitted our written testimony on the needs of America's deaf and blind citizens, successful rehabilitation services provided and our future goals and needs.

With me today I have Mrs. Valerie Dwork, who is a parent and has a daughter who was born with deaf-blindness. Mrs. Dwork is also a member of our board of trustees and is a member of our National Parent Advisory Committee. I would like to have her say a few words about her concerns as a parent of a person with deafblindness, and then if you have any questions we will be very glad to answer them.

## STATEMENT OF VALERIE DWORK

Mrs. DWORK. I am not from Iowa, I from New York, and it is my pleasure to be here. I am here today to give the background or some explanation of how it feels to have a daughter who is 25 years old, who was born during the rubella epidemic of 1964 and has had the disabilities of deaf-blindness developmental disabilities and cerebral palsy.

Fortunately, my daughter Christine was one of the lucky ones. She had the opportunity to attend Helen Keller National Center. The training and support that Christine received at Helen Keller National Association developed her daily living skills, her communication and socialization skills, vocational training and job placement. Needless to say, as the day approached that she was to leave Helen Keller, I had much more and more anxiety because she was leaving the womb, so to speak.

Today, Christine has moved from Long Island up to Schenectady, NY, which is a 200 mile difference from where her home is, and she is doing quite well. Little did I realize, though, when she transitioned out of Helen Keller how prepared she was. I was not, but she was. Her training provided her with a sense of self-esteem and pride similar to most young adults. She was ready to become an independent woman.

Today Christine is able to work, commute to her job by bus, socializes in many activities. Just this past weekend alone she bowled 104. I think that is pretty unique for a deaf-blind crippled kid. She has to—in her community residence she must maintain her own room, do her own laundry and help prepare dinners, and to top off all of these activities Christine is able to commute by airplane from Albany, NY, to Long Island independently. This is quite a feat. She is a person who wants to experience a full life—not a sheltered life, but the pitfalls and the ups and downs that we all experience and grow from and learn from.

This past year I have had the opportunity to become a member of the board of trustees at Helen Keller. I am also an active participant in the national parents network. My involvement with the national parents' network has put me in touch with people throughout the country, parents who have children that are deaf-blind. Unfortunately their situation is not as good as mine.

Many of these clients have transitioned out of all sorts of educational facilities and there does not seem to be any kind of training or placement for them post-21. When they finish their formal education they are at home with their parents 24 hours a day doing nothing. They are left with no occupational, vocational or social services, no social outlets whatsoever.

### PREPARED STATEMENT

I feel not only does the lack of services diminish the training that these people have received, it also demoralizes the human spirit, and what does it say about our tax dollars that have been invested in these people? Where is it going and for what purpose, if we do not have resources so that these people continue on in life?

As a parent of a deaf-blind multihandicapped individual, I urge your continued financial support to Helen Keller National Center and the deaf-blind community.

[The statement follows:]

# STATEMENT OF STEPHEN S. BARRETT, DIRECTOR, HELEN KELLER NATIONAL CENTER FOR DEAF-BLIND YOUTHS AND ADULTS

Mr. Chairman and members of the subcommittee, I appreciate the opportunity to present testimony in regard to our request for your continued support for the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC). For the record, my name is Stephen Barrett, Director of the Helen Keller National Center.

My purpose is to convey to you the urgent need to invest a small portion of this nation's resources in services to a very special population- people who are deaf and blind. Also, to provide you with brief background information on the history and goals of HKNC, recent accomplishments, our goals for the coming year, and implications of chronic financial constraints. I wish to address very specific service priorities in terms of their benefit to persons who are deaf-blind, their implementation, and why we feel they will have an important impact on services on a national basis.

I am accompanied today by Ms. Valerie Dwork who has a daughter with deaf-blindness. Ms. Dwork is also a member of our Board of Trustees and national Parent Advisory Committee. She will share with you some of her concerns as a parent.

The Helen Keller National Center is funded exclusively by Congress. For FY 1991 the Bush Administration has proposed funding for HKNC in the amount of $5.2 million. This inflationary increase is the first proposed by the Administration in many years and is appreciated. Unfortunately, however, over the past several years services to deaf-blind persons through HKNC have been curtailed because of level funding. The FY 1989 appropriation was increased by just .8 of one percent. In FY 1990, the increase was 2%. Because of inflation HKNC has experienced an actual reduction in real terms over the past four years.

## HKNC'S MISSION IS UNIQUE

The Helen Keller National Center is unique, not only in America, but in the world. It is the only national service agency in existence whose sole purpose is rehabilitation training of people with deaf-blindness, one of the severest of all disabilities. The Center is authorized under Title IX of the Rehabilitation Act Amendments of 1986 and operates under the general supervision of the Rehabilitation Services Administration, OSERS, U.S. Department of Education.

In 1986 the Helen Keller National Center Act established an independent authorization for HKNC. The Congress found that:

**(1) "deaf-blindness is among the most severe of all forms of disabilities, and there is a great and continuing need for services and training to help deaf-blind individuals attain the highest possible level of development;**

**(2) due to the rubella epidemic of the 1960's and recent advances in medical technology that have sustained the lives of many severely disabled individuals, who might not have otherwise survived, the need for services for deaf-blind individuals is even more pressing now than in the past;**

**(3) helping deaf-blind individuals to become more self-sufficient, independent, and employable by providing the services and training necessary to accomplish that end will benefit the Nation, both economically and socially;**

**(4) the Helen Keller National Center for Deaf-Blind Youths and Adults is a vital national resource for meeting the needs of deaf-blind individuals and no State currently has the facilities or personnel to meet such needs;**

**(5) the Federal Government has invested approximately $10,000,000 in capital, equipment, and operating funds for such Center since it was established; and**

**(6) it is in the national interest to continue to provide support for the Center, and it is a proper function of the Federal Government to be the primary source of such support."**

The purpose of the Helen Keller National Center is to provide a national program of rehabilitation services to America's estimated 40,000 persons with deaf-blindness. We accomplish this in many ways. During the twelve month period ending June 30, 1989 the Center served over 2900 persons through its (1) rehabilitation center based at its headquarters on Long Island, New York, (2) ten regional offices located throughout the nation, and (3) national network of 28 affiliates based within public and private agencies.

## EXPANSION OF NEEDED SERVICES

An appropriation of $5.5 million for FY 1991 will allow us not only to maintain essential services and training for the most severely disabled of our nation, but will enable HKNC to undertake the following initiatives:

### 1. EXPAND EMPLOYMENT TRAINING PROGRAMS

At present we are limited in the number of employment sites we can establish only by the number of staff we are able to hire. The model of Community Work Experience we utilize, based upon supported employment theory, has already proven effective. We are requesting funds to add two employment training specialist positions who will work directly with our clients on the job site. This will allow us to double the number of job training sites in the community and the number of persons served.

## 2. ADD "SUPPORTED LIVING" SERVICES TO CURRICULUM

Although there are several thousand persons with all kinds of disabilities served by supported living programs throughout the nation, few, if any, are as severely disabled as persons with deaf-blindness. HKNC would establish a national model of supported living for deaf-blind clients which would also be replicated in other parts of the nation through HKNC's Field Service Programs.

## 3. INCREASE SERVICES THROUGHOUT THE NATION

Last year we have begun a process of adding a second person to each regional office based upon recommendations from the Rehabilitation Services Administration, the federal agency under whose supervision we operate. Two new staff have been added, one each to our Atlanta and Seattle offices, and we added a third position which will serve as a Specialist for Elderly Persons with Deaf-blindness.

If our request of $5.5 million is approved, we would add two new positions to our regional offices in order to gradually increase the number of staff in these positions. The result will be a measurable increase in the numbers of persons served in their local communities.

We would also expand our national Affiliate Network which last year served over 1,800 persons. HKNC provides seed money on a temporary basis to public and private agencies in order to assist them in developing specialized projects to serve persons who are deaf-blind.

## 4. IMPROVEMENTS TO PLANT AND MAINTENANCE

HKNC's facilities were constructed with funding provided by the Federal Government and the government retains ownership of the buildings, furnishings, and grounds.

Our current facilities, though modern and well maintained, could benefit from modern technology to effect energy cost savings. Our furnishings in many parts of the three buildings on campus are the original ones installed in 1976. We have begun a plan of action to gradually replace worn equipment and furniture. Our residence building, which provides room and board for a maximum of 52 clients, is badly in need of new furnishings.

### 5. MEET THE ANTICIPATED REQUIREMENTS OF A NEW BARGAINING AGREEMENT

Our current union agreement calls for a salary increase of 5% on July 1, 1990 which also increases our cost of fringe benefits. Without funding to help cover these increases and the normal inflationary increases expected from year to year in any organization, our only alternative would be to eliminate vital staff positions.

### CONCLUSION

Individuals with deaf-blindness are perhaps the most severely handicapped population known to mankind. The Helen Keller National Center for Deaf-blind Youths and Adults provides the highest quality services possible in a program which is internationally recognized as a leader in the field of Vocational Rehabilitation.

On a national basis we are proving everyday that people who are deaf-blind can lead meaningful lives living and working alongside their fellow members of the community. The financial costs of rehabilitation can be measured and the return on every dollar spent has been proven to be a remarkable investment repaid many times over as tax consumers become taxpayers.

Each year brings new ideas, service strategies, and increased opportunities for persons who are deaf-blind. Over the years there has been considerable growth at Helen Keller National Center in terms of both the quantity and quality of services provided. Deaf-blind youths and adults of America need your continued support to help them attain the same quality of life we desire for ourselves.

An appropriation of just $300,000 over the President's budget will be the best investment in human potential this Congress can make. Thank you.

Senator Harkin. Thank you for being here. Thank you for the nice story. You are asking for 5.5?

Mr. Barrett. Yes, sir; the President has recommended a level of 5.2. We would like to see if we could obtain a $300,000 increase above that level.

Senator Harkin. We will see what we can do. Thank you very much for being here.

### STATEMENT OF AL COUTHEN, CONVENTION OF AMERICAN INSTRUCTORS OF THE DEAF, AUSTIN,

Senator Harkin. Next is Al Couthen, assistant principal, Kendall Elementary School.

Mr. Couthen. Mr. Chairman and members of the appropriations Subcommittee on Labor, Health and Human Services and Education, I am Al Couthen, representing the CAID, and I am speaking on behalf of Miss Claire Bugen, who is the president of the CAID, the Convention of American Instructors of the Deaf.

This morning I would like to encourage increased funding for State-operated or State-supported schools, whose responsibility it is to set aside the special educational needs of deaf students.

The administration has recommended no increase for fiscal year 1991. This is not acceptable to us. The vast majority of these programs are not eligible for Public Law 94-142 moneys. Chapter 1 and Public Law 89-313 funds are essential for centers schools to serve the diverse and complex population of students currently in attendance.

This population of students with additional handicaps places severe financial constraints on the provision of quality services. Diverse programming is expensive, and special needs students also demand complex instructionally related service, also additional staff development training, parent education, specialized early intervention, and expensive technological innovations as well.

Mr. Chairman and members of the subcommittee, the Convention of American Instructors of the Deaf is strongly supportive of the goals of Public Law 89-313 funds. We recommend $170 million in appropriations for fiscal year 1991, not $146 million. This increase would provide the necessary resources to meet deaf students' unique education and learning needs.

I would like to add that I am a product of a State school, and I have seen the value of the State schools and I would like to see that with increased financial support.

The second issue that we would like to endorse is the National Institute on Deafness and Other Communication Disorders, which was created by Congress in 1988 under Public Law 100-553. The activities of the Institute include investigation of causes, treatment and prevention of hearing and other communication disorders, research on technology and devices used in the rehabilitation of these disorders and research on environmental agents that influence the communication processes.

The President's budget requests a 4.5-percent increase in NIDCD funding over last year's postsequester level, which was only a 3.2-percent increase over the fiscal year 1990 level approved by Congress. This level requested by the administration is insufficient to continue much of the Institute's current research and would not allow the Institute to generate the critical findings which become the exemplary programs and practices in schools across the Nation.

Deafness is a low-incidence disability and a unique one in the field of special education. The CAID recommends $165 million for the National Institute on Deafness and Other Communication Disorders in fiscal year 1991. For us, the Institute is a think tank, providing data essential to the CAID. We use this data for recommendations and decisions to improve educational services to deaf students.

### PREPARED STATEMENT

In addition, more than 1 in 10 Americans has a communication disorder, making this the most prevalent disability category in the

United States. The NIDCD thus serves not only the deaf represented here by the CAID but also 10 percent of the Nation. This large segment of the population deserves your support and funding.

On behalf of CAID, thank you for this opportunity to present our views on these important concerns.

[The statement follows:]

# STATEMENT OF AL COUTHEN, ON BEHALF OF THE CONVENTION OF AMERICAN INSTRUCTORS OF THE DEAF, AUSTIN, TX

The Convention of American Instructors of the Deaf (CAID) is the oldest professional organization in the United States for teachers, administrators, educational interpreters, residential personnel and other professionals involved in the education of the deaf.

One of the major missions of our organization is to support promising and/or successful educational practices and to examine current issues facing education of the deaf.

This morning I want to encourage increased funding for state operated or state-supported schools whose responsibility it is to satisfy special educational needs of deaf students. The Administration recommends no increase in FY 1991. This is not acceptable to us. The vast majority of these programs are not eligible for P.L. 94-142 monies. Chapter I and P.L. 89-313 funds are essential for center schools to serve the diverse and complex population of students currently in attendance. This population of students with additional handicaps places severe financial constraints on the provision of quality services. Diverse programming is expensive. Special needs students also demand complex instructionally related services, additional staff development training, parent education, specialized early intervention, and expensive technological innovations as well.

Mr. Chairman and members of the Subcommittee, the Convention of American Instructors of the Deaf is strongly supportive of the goals of P.L. 89-313 funds. We recommend $170 million in appropriations for FY 1991, not $146 million. This increase would provide the necessary resources to meet deaf students' unique communication and learning needs.

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The professionals in education of the deaf that CAID represents are dependent on research particularly in the areas of speech, language and audiology to serve their students.

The President's budget requests a 4.5 percent increase in NIDCD funding over last year's post-sequester level, which is only a 3.2 percent increase over the FY 1990 level approved by Congress. The level requested by the Administration is insufficient to continue much of the Institute's current research and would not allow the Institute to generate those critical findings which become the exemplary programs and practices in schools across the nation. Deafness is a low incidence disability and a unique one in the field of special education. The CAID recommends $165 million for the National Institute on Deafness and Other Communication Disorders in FY 1991.

For us, the Institute is a "think tank" providing data essential to CAID. We use this data for recommendations and decisions to improve educational services to deaf students. In addition, more than one in ten Americans has a communication disorder, making this the most prevalent disability category in the United States. The NIDCD thus serves not only the deaf, represented here by CAID, but also ten percent of the nation. This large segment of the population deserves your support and funding.

On behalf of CAID, thank you for this opportunity to present our views on these important concerns.

Senator HARKIN. Mr. Couthen, thank you very much for being here and let me ask you, if the Deafness Institute were to receive the $165 million you are requesting, which is a pretty big increase over last year, how would you like to see the increase used?

Mr. COUTHEN. I would like to use those moneys to expand the research in communication disorders and also in deafness. Right now, they are working on research but I think that needs to include deafness and other communication disorders and also other handicapping conditions.

Senator HARKIN. OK, thank you.

## MICHAEL L. DENINGER, DEAN, PRECOLLEGE PROGRAMS, GALLAUDET UNIVERSITY

Senator HARKIN. Next is Michael L. Deninger, dean, PreCollege Programs, Gallaudet University.

Mr. DENINGER. Good morning, Senator. It is good to see you. I am not from Iowa either, but I will move there if it will help our cause. [Laughter]

I am Michael Deninger. I am here representing the Conference of Educational Administrators serving the deaf, and as you may know, ours is an organization of administrators who head up State-operated and private schools for the deaf, Government agencies, clinics, and other programs serving deaf children and youths. We are over 120 years old, and in some ways we like to think of ourselves as the conscience of deaf education, along with our sister organization, the Convention of American Instructors of the Deaf.

I am here for two reasons today, one is to request that you give your full support to continuation of chapter 1 ECIA Public Law 89-313 funds, and that you do all that you can to support the recommended level of over $146 million for ECIA this year.

I would like to talk a little bit about the programs that are supported with Public Law 89-313 funds. First you are aware that Public Law 94-142 provides funds for students who are handicapped and served by public school systems in this Nation. The State-operated or private residential schools that we represent do not receive any Public Law 94-142 funds unless they are discretionary dollars, but that is clearly a rare instance, so the only source for Federal funds for these center schools, as we call them, are Public Law 89-313 programs.

I would like to give you some examples of programs that currently are funded through Public Law 89-313. One from your home State of Iowa is a computer summer camp that is operated by the Iowa School for the Deaf; in Oregon, training for interpreters in summer programs; in Pennsylvania, career preparation of multihandicapped deaf students; in South Carolina, reading enrichment and language development for deaf students, and other programs that are operated include inservice training, service to the hearing-impaired student.

We are seeing a different kind of student in our center schools these days. Our enrollment, as you may know, has declined over the years since passage of Public Law 94-142, but we are serving larger numbers of multihandicapped students. These are children who are very difficult to serve. Their needs are very complex and it is very expensive to provide the programs that they need.

We are seeing children who are coming out of the hospital these days saved because of the critical care that they get in these hospitals, but also leaving with additional handicaps that we did not see before, so in coming to our schools the children who are infants now are looking very different, and it is much more difficult to figure out how to serve them well.

### PREPARED STATEMENT

I guess I would just like to sum up and ask that the reason for me coming here today is two things. One is, please continue to support ECIA Public Law 89-313, and we are hoping that you can secure at least the recommended level in this year's budget.

Thank you.

[The statement follows:]

### STATEMENT OF MICHAEL L. DENINGER

Mr. Chairman and members of the appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies, I am Michael Deninger and I am here representing the Conference of Educational Administrators Serving the Deaf [CEASD]. The conference is more than one hundred and twenty years old, having been founded in 1868, and our membership includes administrators of schools, clinics, governmental agencies, and teacher training programs serving deaf children, youth, and adults. Many of the members of our conference are administrators in State-operated and private schools for the deaf, sometimes called center schools, which are especially dependent on Chapter I, ECIA (Public Law 89-313) funds for the support of their programs.

This morning, I want to impress on you how much our State operated and private residential schools rely on chapter I, ECIA, funding as a critical source of financial support for special programs. Chapter I funds, the only Federal funds available to Center Schools for the Deaf, support a variety of programs for deaf students at all age levels and the individuals who work with these students. Let me give you a few examples Mr. Chairman—your home State of Iowa has used this funding to support a summer computer camp for deaf students through the Iowa School for the Deaf. Oregon has used chapter I funds to improve the skills of sign language interpreters, and Pennsylvania has supported programs ranging from career preparation for multihandicapped youth, to after-school enrichment programs, to a dormitory learning center. Seattle Public Schools Program for the Hearing Impaired has used chapter I to support a personal computer applications program. Reading enrichment and language development programs for deaf students have been funded in South Carolina.

This morning I would also like to encourage full funding, $146.389 million for programs authorized under chapter I, ECIA. Chapter I funds have made a difference in the quality of services and the morale of the professionals at the center schools. The continuation of full funding is clearly needed.

Most of our center schools receive little or no funding from Public Law 94-142, the only other source of Federal funds for education of the handicapped, except in rare instances when funds may come from the discretionary part of a State's allotment under Public Law 94-142. Public Law 94-142 was enacted to serve handicapped children in our Nation's public school systems. Public Law 89-313 was enacted to serve handicapped children in center schools. When Congress enacted chapter I, ECIA, it guaranteed continued funding for handicapped children in our Nation's center schools and enhanced educational opportunities for handicapped children attending these schools.

Following the enactment of Public Law 94-142, Center Schools for the Deaf in this country experienced significant reductions in their enrollments. Although the numbers of students attending these schools have declined, the enrollment at most of our schools have stabilized and we are now serving significantly higher numbers of students with additional handicapping conditions. These are students whose educational needs are complicated and diverse and who require more intensive programming which is expensive and a challenge to develop and manage. In striving to meet these special needs, chapter I, ECIA funds have been critical to our success. In addition to the programs mentioned before, these funds have supported inservice training, parent education, and services to hearing impaired infants.

Mr. Chairman and members of the committee, the Conference of Educational Administrators Service the Deaf is seeking your support in the form of the continuation of chapter I funds and at their recommended level.

Senator HARKIN. If we get the $165 million that Mr. Couthen asked for——

Mr. DENINGER. We would be delighted.

Senator HARKIN. Thank you very much.

## STATEMENT OF DONALD DEW, PROFESSOR, GEORGE WASHINGTON UNIVERSITY, REPRESENTING THE NATIONAL COUNCIL ON REHABILITATION EDUCATION

Senator HARKIN. Next is Mr. Bill Brownfield—oh, I am sorry. Donald Dew. Donald Dew, George Washington University, representing the National Council on Rehabilitation Education.

Dr. DEW. I am Donald Dew, a professor at George Washington University, rehabilitation counselor in the education program, and have the pleasure of representing the National Council on Rehabilitation Education. We have approximately 100 universities in our membership with 600 councilor educators and researchers.

I just really want to make three points, Senator. First, the NCRE is quite concerned that the 22 million persons with disability in this country receive services from providers who are well-trained, competent, and qualified to provide those services. Second, it is very clear we are not keeping up with the manpower need of qualified personnel who are at the service delivery level, the administrator level, or at the councilor-educator-researcher level.

We are finding that educators and researchers are leaving the universities in the next 5 years at an alarming rate that traditionally have been the individuals that have provided services and education.

Third, we are requesting the $38.52 million funding which will be full funding.

### PREPARED STATEMENT

One other comment that is not in my testimony, but this past weekend about three blocks from here we had 200 counselor-educators, RSA—Rehabilitation Service Administration—personnel and

State agency directors meet to work well into the night to ensure that the moneys that we have now are spent well, services are not duplicated, and it is very clear—that was a very successful conference and it is very clear that we do need the full funding and we are at just about a critical stage, I believe.

Thank you.

Senator **Harkin**. Thank you very much. So $38.520 million. Again, I think in the whole area of rehabilitation services you have to have the professionals out there that know what they are doing.

Thank you very much.

Dr. **Dew**. Thank you, sir.

[The statement follows:]

# STATEMENT OF WILLIAM G. EMENER, PRESIDENT, NATIONAL COUNCIL ON REHABILITATION EDUCATION

The National Council on Rehabilitation Education (NCRE) is an organization composed of educators, researchers, a variety of human resource development specialists, and doctoral students dedicated to quality education and training for a variety of rehabilitation personnel. If adequate numbers of qualified rehabilitation personnel were available, more efficient and effective rehabilitation services could be provided to a greater percentage of our 36 million citizens with disabilities. These services emphasize the minimization of employment barriers faced by consumers, the evaluation and selection of employment/work options, and the maximization of opportunities for living as independently as possible.

It is my pleasure to have this opportunity to testify before this Subcommittee to express the views of NCRE regarding the critical need for knowledgeable, competent and qualified rehabilitation personnel and to support full funding as authorized ($38.52 million) for federally supported rehabilitation education and training, in Fiscal Year 1991.

## CRITICAL BACKGROUND ISSUES

Recent economic recessions have had devastating effects on the lives of our citizens with severe disabilities. Compared to the general population, an escalating proportion of individuals with disabilities have never worked and have been on some form of public assistance. Part of the reason for this high unemployment condition among our citizens with disabilities has been attributed to the shortage of qualified rehabilitation personnel.

Winston Churchill suggested that "The best indication of the civilness of a society is the way in which it responds to its disabled citizens." As a nation, we have been and are committed to this social philosophy, and in turn have enhanced the quality of life on behalf of citizens with disabilities, operationally transformed conditions of social deficit into social contribution, and turned tax consumers into tax contributors. In the 1984 Report to Congress by the Rehabilitation Services Administration (RSA), it was indicated that for every $1.00 spent to return an individual with a disability to work, $10.00 were returned to the tax base upon their placement in the workforce. Further evidence to this societal committment is witnessed by the fact that rehabilitation education and training was first authorized by the 83rd Congress in 1954 (Public Law 565), and since then, federal funds have augmented state and local resources to support pre-service professional education for dedicated rehabilitationists in a variety of rehabilitation disciplines including: rehabilitation counseling, undergraduate rehabilitation services, vocational evaluation and work adjustment, job placement, rehabilitation facility administration, rehabilitation professionals specializing in working with individuals who have unique disabling conditions such as blindness, mobility, ambulatory, auditory and speech impairments, and physicians and paramedical professionals specializing in physical medicine and rehabilitation, among others. In addition to supporting pre-service education and training, federal funds also have been used for continuing education and in-service training of employed rehabilitation personnel to assist them in remaining on the cutting edge of technological and innovative advancements. One important result of this congressional initiative, is that over the past 36 years an impressive synergistic network of education and human resource development programs based in our U.S. colleges and universities, rehabilitation agencies and facilities, and continuing education programs has been developed and utilized efficiently and effectively.

The passage of 36 years has not diminished the importance of and necessity for qualified personnel to provide efficient and effective rehabilitation services. Efficient and effective services are generally directly related to the qualifications of providers. The bottom line is that when an individual with a severe disability goes to a rehabilitation services program for help, it is imperative that that individual be served by a qualified provider. "Qualified" is the key because it indicates that the service provider, in performing his or her duties, is ethical, educated and trained, knowledgeable, professional and skillful. Unfortunately, we have not met this goal.

## IMPACT OF FUNDING FOR REHABILITATION TRAINING

Personnel shortages, advanced technology, turnover rates and retirements in both rehabilitation service delivery agencies and higher education, and the spiraling complexity of services required and demanded by new consumer populations, are among the critical factors contributing to an increasing demand for qualified rehabilitation professionals. For example, persons who previously would have died are now living and children are being born with disabling conditions previously unheard of in our society. An over-riding concern of NCRE is the need for qualified personnel to address the vocational (employment) and independent living needs of persons with disabilities. In addition, a significantly large and growing number of professionals with extensive experience and educational backgrounds in rehabilitation are reaching retirement age; this "aging-out" factor alone may be the most critical problem for rehabilitation services and rehabilitation education in the United States. Thus, IT IS IMPERATIVE FOR US TO BE ABLE TO ATTRACT NEW, TALENTED INDIVIDUALS INTO REHABILITATION SERVICES AND REHABILITATION EDUCATION. Today, qualified women, minorities, and individuals with disabilities are in short supply; economic realities, promotions and upward mobility, and the opportunities for higher salaries in other fields are luring many competent service providers away from rehabilitation services and many doctoral students and new, young faculty out of rehabilitation education.

More trained personnel will not solve all the problems that exist regarding efficient and effective rehabilitation service delivery. However, increased funding for new, highly needed programs and for programs that have outstanding track records for preparing "qualified rehabilitation personnel" and for programs that have integrated innovative approaches and updated curricula to reflect the needs and demands of new consumer populations, we believe, is justified. Education, training and research efforts can have a tremendous positive impact on client services, especially if these efforts are combined with good leadership, professional preparation and operationalized performance standards.

The major concerns for NCRE include the following:

First state vocational rehabilitation agencies continue to experience high annual turnover rates of 14% to 16% in direct service delivery personnel. In our state agencies alone, attrition would consume all of the approximately 1500 graduates currently completing B.S. and M.S. academic programs in rehabilitation. This situation is likely to get worse if we fail to recognize the value and long-range benefits of federal support for rehabilitation education and training.

Second, the demand for professionally prepared personnel is greater than ever before because of changes in the nature of populations now being served in the state-federal vocational rehabilitation program. An increasing number of students involved IN SPECIAL EDUCATION PROGRAMS ARE NOW ELIGIBLE FOR TRANSITION SERVICES, after they complete their public school education, through state rehabilitation agencies. Not only would the provision of efficient and effective rehabilitation services to these individuals enhance their quality of life and render them as tax paying members of our society, but their opportunities to live independently and escape the bondage of the welfare stigma would be greatly increased.

**Third**, we in the rehabilitation professions believe that a crisis situation has arisen relative to recruiting and retaining "qualified" rehabilitation personnel. Many leaders in the field of rehabilitation have estimated that even with $60. million in federal support of rehabilitation education and training, it would take two to three years of implementation and utilization of the funds to meet the needs and demands of today. Moreover, it would be a very sad commentary on our society if, as a result of an insufficient number of qualified rehabilitation personnel, our fellow citizens with disabilities with vocational and independent living potentials, out of sheer necessity, wound up being served by our welfare-type of service delivery systems.

### HIGHLIGHTS OF JUSTIFICATIONS FOR INCREASING SUPPORT

- There are an estimated 7.25 million people of working age (16-64) who have a severe disability (National Institute on Disability and Rehabilitation Research, 1989).
- "Two-thirds of all disabled Americans between the ages of 16 and 64 years of age are not working" (National Council on Disability, Focus, Winter 1989).
- The need for qualified practitioners has been documented. For example, even though master's degree level rehabilitation counselors are more efficient and effective than non-trained rehabilitation conselors (Szymanski & Parker, 1989), less than half of the rehabilitation counselors employed by state rehabilitation agencies have a master's degree in rehabilitation counseling.

### SUMMARY

Rehabilitation is an investment in human resources; it is not a welfare program. It is our best way to demonstrate our civilness as a society. Our citizens with disabilities who have received services through qualified rehabilitation personnel have returned far more in taxable earnings than the program has cost. It would seem to be poor economic reasoning and unhealthy humanitarian concern to minimize the need for competent service providers which are so vital to the delivery of quality services to individuals with disabilities particularly when the ultimate goal is employment and/or self-sufficiency. In his January 20, 1961 Inaugural Address, President John F. Kennedy challenged us by stating, "Ask not what your country can do for you--ask what you can do for your country". Our fellow Americans with disabilities can do, and want to do, many important things for our country. And with the provision of efficient and effective rehabilitation services, our fellow Americans with disabilities will do many important things for our country. It is imperative, however, that our rehabilitation services be provided by qualified rehabilitation personnel-- personnel who have been, and continue to be, professionally educated and trained.

On behalf of NCRE, I appreciate this opportunity to speak in support of full funding ($38.52 million as authorized) for rehabilitation education and training for Fiscal Year 1991. We commend this Subcommittee for the recognition of and insight into the needs of individuals with severe disabilities and the role and value that professionally prepared personnel can have on the employment success of disabled consumers and their efforts to gain employment and independence.

## STATEMENT OF BILL BROWNFIELD, PRESIDENT, NATIONAL REHABILITATION ASSOCIATION

Senator HARKIN. Now, Bill Brownfield.

Mr. BROWNFIELD. Mr. Chairman, I recognize, having seen your support in the past and having heard your comments this morning that I may be accused of what some rural folks refer to as preaching to the choir.

Nevertheless, I thank you for the opportunity to share with you and your colleagues this morning the position of the National Rehabilitation Association as regards appropriations for the programs and the services of the Rehabilitation Act. There are numerous services and programs funded under the act and we address those in our written testimony, with the dollars and the services.

I would like to take a few brief moments to attempt to briefly address the largest service program under the act, the Vocational Rehabilitation Joint Federal-State Program. I serve as the president, but I hope more importantly this morning I sit before you as a person who has been served by VR services in the State after an industrial accident resulted in the amputation of my hand, albeit a very minimal disability, a number of years ago.

I also share with you from the perspective of an individual who received rehabilitation counseling training under the training services of the act, and finally from a position as an administrator of a vocational rehabilitation program in a State that serves 28,000 persons with disabilities a year.

What I would like to say with all that is you are well aware the Harris Poll tells us that two out of every three disabled Americans are not underemployed, they are not employed, and it is the position of VR services that helps us work with those folks.

I believe as a newly disabled person some years ago when I was supported with services, that I could suggest to you that I have over the ensuing years returned back in taxes far, far more than the investment that was made in me.

NRA acknowledges, as I think anyone does, the enormous human potential and the independence that is made possible with rehabilitation services. We also understand well, however, the challenges, as I have sat this morning and listened, you and your subcommittee face in managing the Federal budget.

So let us share with you this morning that this VR program we are urging you to fund at the fully authorized level is very unique. It is a human service program, not just a manpower training program, that goes beyond the training aspect to work with persons with disabilities in all aspects, that has a proven record of payback. Persons with disabilities successfully served with VR services enter into or return to the workplace and return to Government in taxes more than was required to serve them.

The program is cost effective, and in a day of very difficult budget management, we believe that that is an important thing to share with you and your subcommittee. The program services result in taxpayers, as I think Senator Simon said, rather than tax fund recipients.

Time does not allow me to iterate the successes of very disabled persons going to work for the first time following VR services. I am reminded of a young man with an IQ of less than 50 who has now been working 7 years in competitive employment, living independently. If I could share with you the look on his parents' face, even now today, and his, of that kind of freedom as a result of VR services, I think you would understand.

Senator, our written testimony addresses the other exceptional rehab programs funded under the act. If you would allow me to close by saying that your deliberations about funding the programs of the Rehabilitation Act are not one of simply output of public tax funds to help persons with disabilities in need—and that is all kinds of disabilities, the entire gamut, many of whom you have heard from this morning.

### PREPARED STATEMENT

On the contrary, this is one of those unique programs funded in cooperation with the States which represents a provable investment with an exhibited return to the Government. We sincerely urge your full funding of this human investment program. Again, the return on the invested dollar is exceptional.

Thank you again for allowing us to share our thoughts.

Senator **Harkin**. Thank you very much for being here and sharing that with us.

We had $1.528 billion last year, almost $1.529. The authorization is $1.875?

Mr. **Brownfield**. Yes, sir.

Senator **Harkin**. We will do our best.

Mr. **Brownfield**. Thank you, sir.

[The statement follows:]

# STATEMENT OF BILL BROWNFIELD, PRESIDENT, NATIONAL REHABILITATION ASSOCIATION

Mr. Chairman, members of the Subcommittee, the National Rehabilitation Association is an organization whose purpose is solely to advance rehabilitation for persons with disabilities.

The nearly 18,000 members of the National Rehabilitation Association and its seven divisions -- the Job Placement Division (JPD), the National Association of Rehabilitation Instructors (NARI), the National Association of Rehabilitation Secretaries (NARS), the National Rehabilitation Administration Association (NRAA), the National Association for Independent Living (NAIL), the National Rehabilitation Counseling Association (NRCA), and the Vocational Evaluation and Work Adjustment Association (VEWAA) -- express our appreciation for giving us the opportunity to present our views.

## THE REHABILITATION ACT OF 1973, AS AMENDED

The Rehabilitation Act of 1973, as amended, is one of the most complete and well-balanced pieces of legislation in the human services field and a cornerstone in the Nation's effort to assist Americans with disabilities in their efforts to achieve meaningful employment and self-sufficiency.

People with mental and physical disabilities comprise a significant portion of the Nation's population - an estimated 36 million individuals. The size of the disabled population is not static, but continues to grow -- through accidents, injuries, illnesses, and birth defects -- at an estimated rate of 500,000 annually.

Our Nation's past investments in this program have returned significant dividends to our Nation's taxpayers, and more importantly, to the persons with disabilities who receive rehabilitation services. Few, if any, programs funded by the Federal government consistently return so many benefits, both financial and personal, to all segments of our society.

The Rehabilitation Act Amendments of 1986 placed new requirements on the State-Federal Rehabilitation Program. The Rehabilitation Act was amended to (1) require each State Agency to provide Rehabilitation Engineering Services, (2) to assist State Rehabilitation Agencies in the establishment of Supported Employment Service Delivery Programs in each State, and (3) by other changes which, in conjunction with scarce resources, place more pressure on an already-overburdened service delivery system. These are worthy goals. They, however, place additional demands on a service delivery system which is currently overburdened, and only, due to the lack of resources, able to provide services to 1 out of every 20 individuals eligible to receive such services.

In light of the fact that 66 percent of individuals with disabilities aged 16 and over report that their disability prevents them from working and that individuals with disabilities comprise the most underemployed segment of our society, it is vital that State, Federal, and private partners cooperate to provide the assistance necessary for individuals with disabilities.

## REHABILITATION BASIC STATE SERVICE GRANTS

We are recommending an appropriation level of the full authorization amount for the Basic State Vocational Rehabilitation Program, the foundation of the programs authorized in the Rehabilitation Act, as amended, of $1,875.5 million. Throughout its 70 year existence, this program has served millions of Americans with disabilities and has rehabilitated and placed well over 5.5 million people into meaningful, productive jobs.

A national survey of State Vocational Rehabilitation Agencies provides pertinent information as to the ability of the Rehabilitation Program to respond to the existing needs of people with disabilities. The results conclude:

- o In FY 1990, the Federal/State Rehabilitation Program will serve over 930,000 people with mental and physical disabilities.
- o Should the Congress only appropriate the President's request of $1,593.28 million, State Agencies estimate that they will serve nearly 20,000 less people with disabilities, than will be served in FY 1990.
- o Should the Congress appropriate $1,875.5 million in FY 1991, the fully-authorized amount, State Rehabilitation Agencies will be able to serve nearly an additional 150,000 persons with disabilities, an approximately 16 percent increase over the number served in FY 1990.

The benefits accrued from the provision of rehabilitation services may be as intangible as a heightened sense of personal worth, or an tangible as a return on the taxpayers' investment.

## COMPREHENSIVE SERVICES FOR INDEPENDENT LIVING

NRA recommends $14.43 million for the programs under Part A; $30.17 million for Part B; and $6.56 million for Part C, the fully authorized levels. Under Part A of the Independent Living Program, State Agencies provide, or arrange for the provision of, any service which may enhance the ability of a person with a disability to live independently and function within the community and, if appropriate, secure and maintain employment.

Currently, under Part B of the Program, only 40,000 individuals are being served by 146 Federal Grant recipients who operate over 196 locations. Under Part C, grants are provided to State Rehabilitation Agencies and to other public or private nonprofit agencies or organizations to assist older persons who are blind to live independently.

**REHABILITATION TRAINING**

We are recommending the full authorization level of $38.52 million for Rehabilitation Training Programs, a critical element in providing services to Americans with disabilities. Grants are made to help ensure that adequately skilled personnel are available to provide rehabilitation services to persons with disabilities. Because rehabilitation plans are tailored to each person with a disability, vocational rehabilitation depends upon a well-prepared "qualified" professional to deliver a wide range of services.

The President's recommendation of $31.11 million for Rehabilitation Training would not allow the Program to begin to address areas of critical training needs and personnel shortages. Besides not having enough qualified personnel, state rehabilitation agencies are faced with increased demands on their already overworked schedule to meet the call for supported employment, technology, and transition services. Without the increase in funding, the number of grants awarded to experimental and innovative training, continuing education, in-service training, and interpreter training will remain at the same level as in 1989.

**SUPPORTED EMPLOYMENT SERVICES**

The NRA recommends $30.95 million for Supported Employment Services for persons with severe disabilities. The NRA recommends that Supported Employment be funded at the full amount authorized under Public Law 99-506, the Rehabilitation Act Amendments of 1986. This three-year old program holds great promise for securing employment for individuals who have not traditionally been eligible for rehabilitation services. If the fully-authorized amount is appropriated, several thousand additional individuals could be served and employed annually, and States could develop more collaborative funding arrangements to identify sources of ongoing support for individuals with other types of severe disabilities.

**TECHNOLOGY RELATED ASSISTANCE GRANTS**

The NRA recommends that $30.9 million be provided for Grants to States for the newly established Technology-Related Assistance Grants. This program which was created in 1988 was created to increase access to assistive technology devices and services for individuals of all ages and disabilities. Without adequate funds, the states' progress will be impeded, and people with disabilities will continue to be denied access to the tools they need to receive an education, seek gainful employment and participate fully in society. The success of this program depends on the full participation of all the states in developing comprehensive, coordinated systems of service delivery.

## PROJECTS WITH INDUSTRY

We recommend $19.93 million, the fully authorized level, for the Projects With Industry (PWI) Program. The new dollars provided by the increase should be specifically targeted to new and existing projects, thereby allowing the most successful projects to expand their business and industry base to facilitate greater private sector involvement, as well as allowing new and innovative projects the opportunity to replicate the proven success of PWI. Private sector employers benefit from having a pool of trained workers available for existing job slots; people with disabilities benefit from the opportunity to become productive, tax-paying members of society; and the rehabilitation community benefits from management assistance provided by Business Advisory Councils.

## NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH

We recommend that the National Institute on Disability and Rehabilitation (NIDRR) be fully funded at $60.38 million. NIDRR provides for a comprehensive and coordinated approach to the administration and conduct of research, demonstration projects, and related activities concerning the rehabilitation of persons with disabilities. The Administration has already forewarned Congress that if its recommendation of $54.32 million were adopted it would fund less than half of the research and demonstration projects and innovation grants than were funded in 1989, a combined decrease from 82 to 42 grants. At the full authorization level, NIDRR would be able to fund approximately the same number of field-initiated and innovative research grants as in FY 1989.

## CONCLUSION

Mr. Chairman, the Rehabilitation Act and the programs it authorizes signifies our society's recognition of its responsibility to provide citizens with disabilities the opportunity to be full participants in the mainstream of life.

We thank you Mr. Chairman and Members of the Subcommittee in advance for appropriating funds for the Rehabilitation Program at the levels we have recommended in this testimony.

## STATEMENT OF JOSEPH PARRILLO, CHAIRMAN, RESEARCH COMMITTEE, SOCIETY OF CRITICAL CARE MEDICINE

Senator **Harkin**. I am always willing to move people up if they have got a flight problem and they have got to get out and do something. I am glad to honor that. So I will call on Dr. Joseph Parrillo, Rush-Presbyterian-St. Luke's Medical Center, Society of Critical Care Medicine.

Dr. **Parrillo**. Thank you for changing the schedule. I appreciate it. The closest I come to Iowa is that I am from Illinois, which has a border that is similar to yours, so I hope that is close enough this morning.

I am here to tell you about some concerns of the Society of Critical Care Medicine. This is a group of physicians, nurses, and allied health personnel who take care of the sickest patients in this country. We are the people who care for the patients who are in the 6,000 to 8,000 intensive care units in the United States, and we are a multidisciplinary group. We consist of internists, surgeons, pediatricians, and anesthesiologists, as well as nurses, respiratory therapists, and we have well over 4,000 members.

Our concern specifically this morning is the NHLBI—the Heart, Lung, and Blood Institute appropriation—and if it is funded at the present level that is suggested, you will be funding 24 percent of the grants that are being asked for; 24 percent is obviously way down.

Senator **Harkin**. It is the average at NIH, by the way.

Dr. **Parrillo**. Our concern is several-fold. First of all, that is obviously one in four. That means three in four would not be funded.

Second, the number for a young investigator, the person who is going into this field now and needs the funding, commonly the most, is considerably lower than that. Initial grants are funded down around the 10 percent mark, and speaking as someone who trains people in this field, it is very, very discouraging to come up against those types of statistics.

A third issue is that critical area is a relatively new field. It has only been around for about 20 years and, therefore, we do not have the seniority that some of the other fields have and, therefore, we are even at more of a disadvantage.

On the other hand, there are real research needs here, and I do not have the time this morning to go over all of them, but just to highlight a couple, one major issue, for instance, in critical care is how you raise someone's blood pressure when their blood pressure is too low, a syndrome called shock, which is very common and takes 200,000 to 300,000 lives a year, as it stands right now.

We do not know which is the best medicine to use, and yet studies are needed to do this, studies that are multicenter—that is, in several places—and that require a substantial amount of funds and are not going to be done unless some funding agency like NIH or NHLBI funds them. That is just one example of, I could give you literally dozens, but it is I think a good example.

### PREPARED STATEMENT

So my message this morning is to encourage your committee to increase the funding level from 24, we are suggesting 35 percent, as a reasonable level. That way at least one in three would be funded and I think the trainees in this field would find that a much more encouraging number.

[The statement follows:]

# STATEMENT OF JOSEPH PARRILLO, CHAIRMAN, RESEARCH COMMITTEE, SOCIETY OF CRITICAL CARE MEDICINE

The Society of Critical Care Medicine ("the Society") is pleased to present its views on funding for the National Heart, Lung and Blood Institute ("NHLBI") to the Senate Appropriations Subcommittee on Labor-HHS-Education. The Society is particularly concerned with the current rate of awards for approved grants, the lack of full funding of awards selected for federal funding, and the lack of research generally in the constantly emerging field of critical care medicine.

The Society of Critical Care Medicine is a 20-year old, multi-disciplinary organization formed by specialists from Anesthesiology, Internal Medicine, Pediatrics and Surgery. The more than 4,000 members of the Society blend the knowledge, skill and technology from the four medical specialties, nursing, and allied health professions into a coordinated effort to achieve an optimal outcome for critically ill or injured patients. The goals of the Society include improving humane care for patients with acute life-threatening illness and injuries, promoting and developing optimal facilities in which critical care medicine may be practiced, and assuring high educational standards in critical care medicine.

## Critical Care Medicine and Research

A major goal of critical care research has been to develop a method of predicting which patient will benefit from the critical care environment. Some patients develop an acute illness that can clearly be effectively treated by applying the technology available in an intensive care unit ("ICU"). Others have an illness so life-threatening, it unfortunately cannot be reversed by any known treatment available in medicine. Most patients, however, fall between these two extremes, and as candidates for admission to an ICU facility, there is considerable ambiguity as to whether ICU technology can, in fact, reverse their acute illness. Moreover, the monitoring and therapeutic intervention available in an ICU have certain inherent risks. Increased emphasis must be placed on developing methods to define prospectively who will benefit from intensive care with a reduced morbidity and mortality.

## Increased Award Rate for Approved Grants

The Society recommends appropriations sufficient to allow an award rate of 35 percent of approved research grant applications, with full funding of the awards, thereby eliminating the so-called "downward negotiation" of 13 to 17 percent typical after grants win funding approval. The funding of additional competing investigator initiated research projects will allow the Institute to pursue several initiatives in both basic and clinical research. Only 24 percent of approved grants would be funded under the proposed budget for the NHLBI, an inadequate level to sustain the progress made thus far. More disturbing to the Society is the fact that new grants, often applied for by young scientists who represent the future of our field, would be hard pressed for federal funding. Critical care research is still a comparatively new field and would suffer greatly under this budget.

## Expanded Research in Critical Care

Research efforts in critical care are vast, yet certain key areas should be pursued with increased interest. Critical care medicine is a multidisciplinary subspecialty, and research efforts should be more cognizant of this characteristic. The Society recommends that increased interest should be paid to multidisciplinary teams of internists, surgeons, pediatricians, anesthesiologists and basic scientists interested in critical care who work together to answer the common problems encountered in the ICU.

Many of the most important questions facing critical care medicine have not been investigated. For example, vasopressor agents are frequently used to treat shock; however, no large clinical perspective trial has ever evaluated the important outcomes of using different pressor agents. Randomized studies may be difficult to carry out within a single unit or institution for many diagnoses because of the ethics and logistics of patient consent and the need to act quickly. However, if multi-center trials can be performed evaluating thrombolytic therapy in acute myocardial infarction, then multi-center trials can be carried out to evaluate very common critical illnesses. In fact, the 1983 NIH Consensus Conference on Critical Care Medicine recommended that such randomized studies be conducted by enrolling more than one ICU or institution to participate by randomizing units or institutions, not patients. Such multi-center studies would have the ability to answer some of the most pressing issues in critical care medicine today.

The Society also wishes to emphasize that more clinical investigation is needed in this field. Clinical investigation must be carried out by physicians who are trained in the care of critically ill patients and know how to perform investigations in these same patients. More emphasis needs to be placed on the training and subsequent support of such academic critical care physicians.

Many previous studies in critical care medicine used improvements in physiological perimeters as the primary outcome variable. More emphasis needs to be placed on the most important outcomes, i.e. decreased severe morbidity and/or mortality. Only by knowing whether such interventions influence overall long-term morbidity and mortality will we know whether or not such interventions are, in fact, efficacious.

## Conclusion

The Society of Critical Care Medicine believes that only through an increase in appropriations substantially above the President's request can NHLBI meet its stated goals for advances in research and training for cardiac and respiratory research. The Society recommends that this subcommittee provide the NHLBI with the financial means to fully fund a greater percentage of research grants and encourage the Institute to support increased research into critical care injury and illness, both at the intramural and extramural level.

Certain problems in critical care medicine will be solved only by a better understanding of the underlying pathophysiology of basic disease processes. Only through a combined, multidisciplinary effort will we understand the process of vessel cell injury in multiorgan system failure, the profound vascular and heart abnormalities of sepsis, and the mechanisms of brain swelling in head injury. Emphasis should be directed at investigating these disease processes that are central to our understanding of many critical illnesses. Encouragement from this committee will, in the Society's view, result in significantly improved patient care in this country's critical care units.

Senator **Harkin**. As I said, you know, 24 percent is the average at NIH. They are all way too low, getting one out of every four.

Does the society support the medical effectiveness research effort at the new Agency for Health Care Policy Research? We put in a provision last year to fund a medical effectiveness effort to find out what types of care really are effective and to do a research program on that, to find out—intensive care, for example, some procedures may be more effective than other procedures, and we have not really looked at which ones are more effective and which ones are not.

Dr. **Parrillo**. We are very much in favor of that. In fact, critical care is one of the fields that when it was formed 20 years ago, one of the areas we initially got into early, was we realized that intervention in the ICU was clearly helpful for a certain group of people. I mean, you did not need any study. There was no question about it.

Then there was a group of people where it was not helpful at all, and then, of course, there is the 85 percent in between where you have an intervention that will improve a physiological perimeter—blood pressure, or something like that, but did it, in fact, make the person feel better in the long run, and did it make mortality lower, did more people survive? Those types of studies have been done in ICU's now for about 15 years. The problem is that you really need a large number of people to be in the study, and it cannot be done at one place.

The NIH Consensus Conference on Critical Care, which I chaired back in 1983, identified five or six bit projects that needed to be answered. These are actually cost effective in the long run, because if you are using a therapy that is not effective, obviously you can then not use that any more, if you have a piece of proof that costs very little in order to show that.

Senator **Harkin**. Thank you very much.

### STATEMENT OF HOWARD E. "ROCKY" STONE, EXECUTIVE DIRECTOR, SELF HELP FOR HARD OF HEARING PEOPLE, INC.

Senator **Harkin**. Next is Howard Stone, executive director—we will take about a 5-minute break.

[A brief recess was taken.]

Senator **Harkin**. The subcommittee will resume its sitting. We now have Howard "Rocky" Stone who is here with us today, and a long-time friend, someone that I recognize for being a pioneer advocate for people who are hard of hearing, who has made the Self Help for the Hard of Hearing a model consumer organization for persons with disabilities.

Every group should replicate what you have done to have the maximum amount of input. You have done a great job, and I want you to know it has not gone unnoticed by a lot of us and we appreciate it very much, and we are glad to have you here today on behalf of Self Help for Hard of Hearing People, Inc. Again, congratulations on all you have done.

Mr. **Stone**. Thank you very much. I would like to mention I have been severely hearing impaired for 30 years and profoundly deaf for the last 15, but I still function in the hearing world with the aid of this device, and I have severe, constant, shrill, high-pitched tinnitus. Now, however you pronounce it, it is a problem. It is a big one.

Anyway, last year when I was here I mentioned that I thought that the new National Institute on Deafness and Other Communication Disorders had a wonderful opportunity to break some new ground in the areas of deafness and hearing impairment, and I am very happy to report this morning that they are beginning to do that. In a major research call that was sent out for three or four, depending on funding, research and training centers, the call differs significantly from the usual NIH offering in three ways.

The first way is that this particular call insists on dissemination of information to the consumer. NIH never does that. Second, it insists on innovative and creative ways for interaction between training and research, which is unusual for NIH, and third, it urges affirmative action and utilization of people with disabilities in the actual research process, which is another new thing in an institute at the National Institutes of Health.

This is a very encouraging kind of development, and it is one of the things that I offer as evidence for increasing the funding in that particular Institute, which because of the projects that it has inherited and the kind of mission that Congress has given to it, it simply does not have the resources at the time to do the various jobs that it is supposed to effectively.

As encouraging as that is, however, we know that we have got an awful lot of research catching up to do. If you read the draft document entitled "Promoting Health, Preventing Disease, Year 2000 Objectives for the Nation," you see a woefully inadequate treatment of hearing loss and an unawareness of what is really required in terms of the health of the Nation as it relates to hearing loss, and how hearing loss impacts on our health across many different areas.

So because of both the promise and the need, SHHH strongly supports a budget figure of $165 million for the National Institute on Deafness and Other Communications Disorders.

We are active with the Vocational Rehabilitation Organization and the Rehabilitation Services Administration and the Department of Education, and all of those areas over the last 6 or 7 years have become increasingly aware of the needs and the differences of approaches required in handling deaf people versus hard-of-hearing people. We work very closely with organizations of the deaf as you know, but we require a certain amount of consideration just to handle the problems peculiar to the needs of hard-of-hearing people.

In the work force, there are a large number of people being lost to American industry because they lose their hearing at the age of 40 or 50, and rather than go through the hassle of trying to cope with that problem, much of which they do not know themselves, they simply leave. They are not forced out, they quit. In a short labor situation, we are trying to encourage vocational rehabilitation to understand that job maintenance is a priority, as well as job acquisition.

Our written testimony supports a variety of other programs at specific budget levels, but I did want to mention those two things regarding the National Institute and vocational rehab.

The Architectural Barrier and Transportation Compliance Board also requires an increase if they are going to carry out their new responsibilities when the Americans with Disabilities Act passed. They simply do not have the resources or the personnel to carry out their responsibilities that they will be faced with and the implications of that act are so profound and the considerations of implications as opposed to passage is so little at the moment that people have not had really time to think about it. We do need more money for that to implement the act properly.

### PREPARED STATEMENT

Senator HARKIN. Thank you very much.

Mr. STONE. I do not want to leave before expressing our appreciation of HHS and you personally, for your deep commitment to the concept of fairness and to the principle of equal opportunities for all American citizens.

Senator HARKIN. Thank you very much, Rocky. I appreciate it. Thanks for being here.

[The statement follows:]

## STATEMENT OF HOWARD E. STONE, EXECUTIVE DIRECTOR, SELF HELP FOR HARD OF HEARING PEOPLE, INC

My name is Rocky Stone and I am the founder and Executive Director of Self Help for Hard of Hearing People, known as SHHH.

As you know, we are a volunteer, educational organization with members in all fifty of the United States. Our mission is to seek out those who suffer from hearing loss; involve them in local meetings and activities; educate them about the problem; instruct them about detection, management and possible prevention of further loss. We have organized a constituency of hard of hearing people to join forces with the existing deaf communities to push for research into all elements of hearing loss and to raise the quality and lower the price of remedial aids.

We work to develop public and professional acceptance of the needs of hard of hearing people, fostering a climate in which we can seek appropriate alternative communication skills. And SHHH urges government at all levels to rectify existing inequities suffered by people with disabilities.

Mr. Chairman, the National Institutes of Health tells us there are 28 million hearing impaired persons in the United States. Two million are deaf, the other 26 million have varying degrees of hearing loss. I appreciate the opportunity to be with you today, to share some good news as well as our recommendations for the FY 1991 Budget, on behalf of that large constituency.

First, NIDCD. Last year when I appeared before this committee, I said that the NIDCD had an opportunity to break new ground in the area of deafness and hearing impairment. I am happy to inform you that it has done so. In a major call for Research and Training Centers, NIDCD has gone beyond the usual NIH offering in three major ways: dissemination of research information to the consumer is stressed; involvement with persons having deafness or hearing impairment is urged and research and training are interactive with emphasis on innovation.

In addition to this encouraging sign, a permanent Director with outstanding professional qualifications is building on the excellent foundation laid by the Acting Director. And yet, we have a lot of research catching up to do as witness the woefully inadequate treatment of hearing loss in the draft document entitled, Promoting Health/Preventing Disease: Year 2000 Objectives for the Nation. As a result of both the promise and the need, SHHH strongly supports a budget figure of $165 MILLION FOR FY 1991 FOR NIDCD. The level requested by the Administration is insufficient to continue much of the Institute's current research and would not begin to address Congressional concerns about the need for more basic and specialized research. The critical need for more researchers--in particular the training of minority candidates for research positions in the communication sciences cannot be met without increased funding. Last year, NIDCD developed a long-range plan to implement recommendations for dealing with "critical research training" needs. Yet, the budget request does not allow for dealing with these needs.

More than one in every 10 Americans has a communication disorder, making this the most prevalent disability category in the U. S. As the population ages, the prevalence of communication disorders will continue to grow rapidly. Also, an increasing number of infants and small children, particularly those in lower socioeconomic circumstances, suffer from hearing and speech disorders. Congress estimates that communication disorders cost the U. S. economy $30 billion a year in lost productivity, special education costs and health care costs. Dr. James Snow, Director of NIDCD, has testified on the need for research initiatives in numerous areas, including noise exposure--the most preventable cause of hearing loss. Our recommendation, far better than the President's request, will provide the resources necessary to pursue these important initiatives. The increase is absolutely necessary if NIDCD is to carry out its mission of research and training on behalf of the large and growing population of Americans with deafness and other communication disorders.

Other SHHH recommendations for FY 1991 are:

VOCATIONAL REHABILITATION STATE GRANT

We recommend $1,875.5 million.

REHABILITATION SERVICES TECHNOLOGY-RELATED ASSISTIVE GRANTS

We recommend $30.9 million.

EDUCATION OF CHILDREN WITH HANDICAPS (STATE AND LOCAL PROGRAMS)

We recommend $3,493 million.

SPECIAL EDUCATION TECHNOLOGY

We recommend $11.9 million.

ARCHITECTURAL AND TRANSPORTATION BARRIERS COMPLIANCE BOARD

We recommend $2.75 million.

Mr. Chairman, SHHH supports increased funding for all federal programs, especially within the National Institutes of Health and Office of Special Education and Rehabilitative Services, which impact on the delivery of services for people who are deaf and hard of hearing.

Thank you for providing this opportunity to be heard.

## STATEMENT OF PETER PUTNAM, RECORDING FOR THE BLIND, INC.

Senator **Harkin**. Next is Peter Putnam, here representing the Recording for the Blind, Inc.

Welcome to the subcommittee and please proceed.

Mr. **Putnam**. I want to express my congratulations and thanks for your sponsorship of the Americans for Disabilities Acts, because I think that is a way of tapping one of the most underutilized resources in the country.

It is not necessary to have Recording for the Blind to overcome the challenge of blindness. I will remind you that two of your predecessors, about 75 years ago, were blind: Thomas Gore, the grandfather of the present Senator, and Thomas Shaw from Minnesota, who were blind men. But Recording for the Blind has done a tremendous job, I think, representing an important partnership.

I am going to be personal for a second. I went blind in my junior year in college, in 1941, and I was able to get back into the college I attended, which happened to be Princeton, but I know darn well they would not have accepted me if I had been applying blind. Deans of admission just did not want to take the responsibility. The thing that opened the floodgates was World War II, when the blind veterans, under the GI bill of rights, deans of admission could not say blind men cannot go to college. And when they did that Recording for the Blind began, recording textbooks for blind veterans. That was its initial impulse, but it went on to civilians of all kinds and of all academic levels. So we serve everybody now, and we serve them with volunteer readers, which I think is tremendously important.

About one-half of our budget is contributed services by volunteers who can read all kinds of difficult books, different languages, computer manuals, physics, chemistry, hard sciences and so forth, where we have a big pressure now, in cooperation with the National Science Foundation and the AAAS, American Association for the Advancement of Science, to record more science books, particularly in secondary schools, so that our students can get into college and get on the scientific track.

### PREPARED STATEMENT

When I went to college—we have no idea how many people there were in college who were blind at that time: 50, 100—there are no statistics. Today, we are serving 8,000 in college. Last year, we provided 24,000 people with educational books. As a matter of fact, one book went out of our national headquarters, better than one book every minute of every working day, and we answered 98 percent of the requests that came in through our national headquarters within 48 hours. We have 75,000 books in our master tape library—those are books that have already been recorded, and then we have studios around the country that record new books for students. Obviously, you have to keep a library growing at all times.

[The statement follows:]

## STATEMENT OF PETER PUTNAM, RECORDING FOR THE BLIND, INC

Mr. Chairman and Members of the Committee:

Recording for the Blind (RFB) is a nonprofit educational service organization which is the only national resource in the United States providing, free of charge, textbooks (no matter what their degree of difficulty) on cassette tape to blind and perceptually and physically handicapped students at all educational levels, from fifth grade through postgraduate training.

RFB was founded in 1948 by Anne T. Macdonald to help blinded World War II veterans take advantage of educational opportunities under the G.I. Bill. Before that time, blind students rarely attended college. Since its establishment RFB has evolved to be the primary source of educational material for print-handicapped students of all ages (except the very young), in all fields. RFB's guiding principle is that print-handicapped individuals must have available to them any educational texts that are available to their sighted and able-bodied peers, including law, medicine, sciences, mathematics, and foreign languages. RFB believes access to "learning through listening" is a right, not a privilege.

Since its inception, RFB assisted in the education of blind and other print-handicapped students by providing 2,000,000 books to 200,000 readers. RFB's extensive library, currently valued at $162 million, comprises the largest and most comprehensive collection of recorded books in the world. The Master Tape Library includes 75,000 titles, a number which increases by 3,000 new books each year, recorded by 4,000 volunteers at 31 recording studios in 16 states and the District of Columbia. Blind and other print-handicapped students from all 50 states and the District of Columbia have access to this wealth of knowledge. Last year RFB provided 140,000 taped books -- one every working minute -- to 24,000 borrowers. About 95 percent of these were shipped to borrowers within 48 hours of the request.

The demand for taped texts is growing steadily each year. Increasingly, RFB receives requests for technical books in science, mathematics, and engineering. In earlier years the bulk of the texts recorded were in the liberal arts such as classical literature, history, and the social sciences. Since most of the classics are now available from RFB's Master Tape Library, and since blind students are more and more entering specialized fields, the recording emphasis has shifted; now some 60 percent of the books recorded are in scientific areas which require three times as long to record as nontechnical books, and must be periodically revised in new editions. RFB currently is collaborating with the National Science Foundation and the American Association for the Advancement of Science to identify volunteer scientists to record these technical books.

To help meet this growing demand and prepare for the future, RFB recently completed an equipment modernization program to expand its computer system, install automated library shelving, and purchase state-of-the-art tape duplicating equipment. New recording studios have been open in Boston, New Haven, Los Angeles, and Philadelphia which are devoted to the recording of technical and scientific books. Although RFB is heartened by the dramatic increase in demand for science and technical books among blind students, the cost burden to RFB increases substantially, year by year.

RFB provides, through the private sector, an essential educational service, free of charge to borrowers which the Federal government or state governments would otherwise be required to provide. Because of its nationwide network of 4,000 trained volunteers, RFB can fulfill its mission more efficiently, more effectively, and with far less expense than a government agency. Las year RFB volunteers donated services computed at a value of $7,284,000, equal to one half of RFB's total budget. RFB is a volunteer organization in the truest sense.

Two complementary (not duplicative) educational organizations -- the Library of Congress' National Library Service for the Blind and Physically Handicapped, and the American Printing House for the Blind, are supported exclusively or primarily through federal funds. In contrast, RFB was able to raise $6,743,250 from private sources in 1989, and received sole source contract funds of $850,000 from the U.S. Department of Education's Office of Special Education Programs. Congress appropriated funds to increase this amount to $1.35 million for FY 1990.

As the primary nationwide source of recorded texts for blind and other print-handicapped students, RFB must continue to meet the growing demand; it is no exaggeration to state that a college education would be extremely difficult, if not impossible, for any blind student without the free borrowing services of RFB and its fast response time, enabling blind students to compete in class with their sighted peers.

Also, through its librarians RFB is able to search its library of 75,000 titles and prepare bibliographies for blind students undertaking research. This capability exists nowhere else in the world.

When RFB first received a Federal contract in 1975, the $500,000 amount provided about one-third of RFB's support. Since that time, demand (and expense) have increased to the point that even with the substantial increase Congress provided for FY 1990, the amount will provide only 20% of RFB's operating budget. RFB will continue to rely mainly upon private sources of funding, and revenues from these sources are expected to expand in the future; but an expanded and stable commitment of Federal support, commensurate with the national interest in maintaining the unique services RFB provides, is essential to assure excellence in education for blind students.

We wish to assure this Committee that, while we are seeking further federal funding from Congress, RFB is making every effort to assure its own financial good health by undertaking a five-year campaign to raise $30,000,000 from non-public sources. It has evolved a business plan which outlines the goals of the campaign and the strategy for reaching them. This campaign will not only enhance the services of RFB, but also create an endowment to assure the continuance of such activities as RFB's full library service.

Since RFB is in the business of preparing print-handicapped persons to lead independent lives and to become productive citizens in the nation's economic mainstream, RFB's service indirectly produces revenue for Federal, state and local government by enhancing employment opportunities for the blind, and thereby provides tax revenues for these governments. Public Law 94-142 requires the Federal government to provide educational services for all handicapped children. As mentioned previously, if RFB did not exist, the Federal government would have to provide the services. It could do so only at great expense, if indeed it could do so at all. Therefore it is reasonable and fair for the government to share a significant proportion of the cost of RFB's operation. RFB urges an appropriation of $2.5 million for FY 1991, an amount which would provide about 18% of RFB's total expenses, including the value of volunteer services.

Recording for the Blind, Inc. appreciates the efforts of this Committee in supporting RFB's services, and is grateful for the opportunity to submit testimony on FY 1991 appropriations.

Senator HARKIN. Where are you located physically?

Mr. PUTNAM. Physically, the master tape library is located in Princeton, NJ. We have studios all around the country. We have 31 studios. We do not have one on Iowa, but——

Senator HARKIN. That is all right. [Laughter.]

Mr. PUTNAM [continuing]. We will. And we have cooperated with the National Library Services in order to engineer a new type of cassette which is much more effective. We have worked with the Office of Special Education, had a very good representation there, but we also—we raise most of our money from individuals and from hundreds of foundations and hundreds of corporations. So it is a meshing of the public and private and charitable and individual sectors, which I think—consider is great partnership. I would like to also say, we put in a brief to you, but one thing it neglected to say, in 1975, to duplicate a book from our master tape library, including every and all administrative overheads—the lights, everything else, cost $33, the average book. Today, it costs $36 which is only a 9-percent increase, and I consider that is pretty effective management. And, therefore, I strongly urge that you help us out.

Incidentally, I did think of an Iowa connection. A gal named Sylvia Nemmers, last year, was from Iowa, a wonderful gal. She wrote and said that my parents are very good with blindness. When it took me twice as long to do anything, they told me I was learning patience. When I failed at anything, they told me I was learning perseverance. When my classmates teased me, they told me I was learning character. And with patience, perseverance, and character, she graduated, not from Iowa—she went to the University of Kansas—but graduated as a chemist.

And I think what is terribly important is to realize that computers, with synthetic speech now, put in the hands of the blind an invaluable learning tool and working tool, a vocational tool. So, with computers you can do all kinds of things—computers that talk.

Senator HARKIN. That is a great story. She just graduated last year you said.

Mr. PUTNAM. Yes; a wonderful gal.

Senator HARKIN. Nemmers?

Mr. PUTNAM. Nemmers, N-e-m-m-e-r-s, Sylvia Nemmers.

Senator HARKIN. That is the kind of patience, perseverance and character that Iowans have. [Laughter.]

Mr. PUTNAM. I am all for that.

Senator HARKIN. Thank you very much for being here. Anything else you want to add? I appreciate it.

And you are recommending $2.5 million for the Recording for the Blind. Last year it was $1.350 million. We will do the best we can.

Mr. PUTNAM. We certainly appreciate it.

Senator HARKIN. Thank you.

## STATEMENT OF BEVERLY KIEFER ON BEHALF OF THE COALITION FOR HERITABLE DISORDERS OF CONNECTIVE TISSUE AND THE NATIONAL MARFAN FOUNDATION

## ACCOMPANIED BY PRISCILLA CICCARIELLO, PRESIDENT, COALITION FOR HERITABLE DISORDERS OF CONNECTIVE TISSUE

Senator HARKIN. Next, Beverly Kiefer. I met Beverly before. Thank you for being here, Beverly. Again, she is from Iowa representing the Coalition for Heritable Disorders of Connective Tissue and the National Marfan Foundation.

Now, let me just ask you before you start, now the Coalition for Heritable Disorders, you cover all kinds of things, like epidermis——

Ms. KIEFER. I thank you for the opportunity to present testimony on behalf of more than 500,000 Americans afflicted with heritable disorders of the connective tissues and the many more that do not know they have this disorder. As I said, I am Beverly Kiefer from Indianola, and I am affiliated with the Coalition for the Heritable Disorders of Connective Tissue and of the National Marfan Foundation.

The coalition was founded to bring about greater awareness of these diseases. There are more than 100 such disorders. One of these disorders is the Marfan syndrome, and I would like to tell you, personally, why your support is very important to me.

On October 30 of last year, our phone rang at 4:30 in the morning and—this is not every parent's nightmare, even if your kids are all married—it was our daughter-in-law Lynn, calling to tell us that our 32-year-old son, Scott, was hospitalized at Mercy Hospital in Des Moines with severe chest pains and could we come right away. Of course, we left.

This could not be true. Scott has always been a super, healthy, young man. Never a history of any kind of heart problems. He had been a U.S. Marine for 4 years; he was a member of the Iowa National Guard. He is an avid runner, a rock climber, a rappeller, and a very physical young man.

At the hospital, an EKG was done and a new murmur had been detected, and he had never had a heart murmur. An echocardiogram was done, and it showed an aortic aneurysm. An angiogram then showed that the aorta had ruptured and the aortic valve was destroyed. It was a miracle he was still alive.

Our cardiac surgeon was Dr. Robert Zeff, and he gave him and us a 50–50 chance of survival with surgery. Without surgery he would die within a few minutes. It was a very high-risk surgery. It was an 8½-hour surgery with some very serious complications. His aortic valve and his ascending aortic was replaced, and his coronary arteries are now connected to his artificial aorta. And he also has lost a kidney due to another aortic dissection.

He was in extreme, critical condition. And as a parent, can you imagine what we were going through? He has also now had a permanent pacemaker implanted and the diagnosis was Marfan syndrome.

In November, the next week, my husband and two daughters — my daughters are 30 and 26—were diagnosed as having Marfan syndrome, as well as four of my six grandchildren, who are ages from 11 to 1½. My world fell apart. At least, we are now aware of their condition and the cardiologist will monitor them closely, and hopefully they will never have to undergo the emergency surgery that Scott did.

I am happy to say that, after some very anxious days, our son did recover. He will never be quite the same, but we are very fortunate to have him. He has returned to work as a reporter at the Boone Newspaper in Boone, IA, and he will complete his masters' degree at Drake University in Des Moines in May. He is married and has two small daughters, and of course, their lives have changed dramatically. His love for physical sports is over, and we have to realize that his lifespan has been shortened.

Most people die of Marfan syndrome immediately, and the coroner usually makes the autopsy. If only doctors had been more aware of this disorder, our son would have never been in the condition he was.

We are hoping for a test to be available in a few years with continued research. In April our whole family will participate in a research program with Dr. Peter Byers. Without your continued support, this would not be at all possible.

## PREPARED STATEMENT

In Iowa we are fortunate to have Mercy Hospital and cardiac surgeons like Dr. Stephen Phillips, Dr. Robert Zeff, and their associates. At Mercy Scott was known as the miracle man from everybody, from top to bottom. And I ask you personally, for your continued support in funding the National Institute of Health and Research on the Marfan syndrome. We are asking for $5 million for basic research, R01 grants for heritable disorders of connective tissues, and I thank you.

[The statement follows:]

# STATEMENT OF PRISCILLA CICCARIELLO, PRESIDENT, COALITION FOR HERITABLE DISORDERS OF CONNECTIVE TISSUE

Mr. Harkin and members of the United States Senate Labor, Health and Human Services, and Education Appropriations Subcommittee, I thank you for the opportunity to present testimony on behalf of the more than five hundred thousand Americans afflicted with heritable disorders of connective tissue.

I am Priscilla Ciccariello, President of the Coalition for Heritable Disorders of Connective Tissue, Chair of the National Marfan Foundation, and a Board member of the National Organization for Rare Disorders.

The Coalition for Heritable Disorders of Connective Tissue (CHDCT) was founded in 1988 in order to: bring about greater awareness and understanding of heritable disorders of the connective tissue in the medical professions and in the public at large; to encourage teaching in the schools training health practitioners that will help them to identify, diagnose, and treat the various heritable connective tissue disorders; and, to foster and support research. There are more than one hundred (100) such disorders which are heterogeneous and have problems concerning syndromic boundaries and classification. Although each connective tissue disorder is rare, approximately one half million (500,000) Americans are affected by them as a group.

Within that group, approximately 30,000-40,000 Americans such as my family are affected by Marfan syndrome. This genetic disorder, which is potentially fatal or severely disabling, is characterized by tall stature, long limbs and fingers, scoliosis, cardiac complications (the most common is aortic aneurysm), and subluxation of the lenses of the eyes.

Because of a lack of knowledge about this condition many persons who have it go years without diagnosis. All too often, this leads to an untimely and unnecessary death. One such person was Flo Hyman, the U.S. Olympic volleyball player who died in January of 1986 of a ruptured aortic aneurysm associated with Marfan syndrome. I met Flo's sister at the National Marfan Foundation Conference in August 1986. She told all of us how Flo had gone undiagnosed all those prior years even though she had numerous physical exams. Flo's sister went on to tell us that the family was never informed that Marfan was an inherited condition - even after Flo's death. It was only after a sports writer covering the story told her there could be a fifty-fifty chance of other fmaily members having it that her brother was diagnosed and was found to have an aorta close to rupturing. He did have subsequent successful surgery.

My own son was diagnosed at autopsy (age 22) and my husband died at age 59 from complications of Marfan syndrome. Two of my other sons and several of my grandchildren are also affected. Those of us in the National Marfan Foundation hear these stories of tragedy time and time again. Sadly, these stories repeat themselves for those affected by other heritable disorders of connective tissue as well as by those 20 million Americans who are affected by any of the 5,000 known rare disorders. The report of the National Commission on Orphan Diseases submitted to Congress last year stated that more than fifty percent of patients with rare diseases went more than five years (some more than 10 years) without a diagnosis of their disorder.

This Report to Congress confirms the critical needs of all the families I represent today:

(1) There must be greater medical education about heritable disorders of the connective tissue such as the Marfan syndrome.

(2) The National Institutes of Health must be adequately funded in order to provide both intra and extra mural clinical and basic research on heritable disorders of connective tissue and other rare diseases.

(3) Clinical research centers should be established throughout the country for diagnosis, treatment and research on heritable disorders of the connective tissue.

Little is known about Marfan syndrome and other heritable disorders of connective tissue because there is virtually no clinical or basic research underway. We believe that the time has come for the National Institutes of Health to do something to fill the unacceptable gap in diagnosis, treatment and research. Without dollars spent in this vital effort, we Americans who are unfortunate enough to have a genetic disorder will have no realistic hope for new treatments and investigations to find the causes and eventual cures for our conditions.

In April of this year the National Institute of Arthritis and Musculoskeletal and Skin Diseases will host a workshop on Heritable Disorders of the Connective Tissue. We are grateful that NIAMS can, for the first time in a decade, bring prominent researchers together to discuss the current state of research and propose the direction(s) for science in this area for the coming years.

With an adequate budget for NIH programs in general and NIAMS in particular, research could be initiated which would eventually save lives and suffering for many thousands of families. Where can we turn, if not the NIH? Without adequate funding for and from the NIH the findings and recommendations from the 1990 NIAMS Scientific Workshop on Heritable Disorders of Connective Tissue will have no meaning.

We are worried for our families today and for our future generations. Biomedical researchers working on both rare and common diseases agreed that it is harder to get funding for rare disease research than for research on a prevalent disease. Researchers feel that the lack of funding is the single greatest barrier to discovery of treatments for rare disorders. The pain, suffering, and loss incurred by families affected by Marfan syndrome and other rare diseases is no less than those affected by cancer. Why does this go unacknowledged by our government?

We are also concerned about the future of all bio-medical research in this country. Without funding for meritorious scientific studies and for encouraging and training new researchers the research professional will be left with far too few qualified people to ensure America's health.

U.S. research dollars would be well spent on Marfan syndrome and other heritable disorders of connective tissue. With genetic research technology advancing so quickly, there would be a good chance of finding genetic markers and subsequent answers about treatments.

Without the basic and clinic research, Americans stricken with Marfan syndrome and other rare genetic disorders have little hope for survival. I refer not only to basic survival, but to a quality of life that enables families to survive together. The toll taken by these illnesses is enormous, both financially and emotionally. Families can be devastated since multiple family members are often affected. In many cases the wage earner dies leaving the partner with several children in need of ongoing medical care and treatment. Drug therapies, the only treatment now known, can cost several thousand dollars per year, life long. Additionally, the open heart surgery, needed in many cases, costs thousands of dollars. All too often these families are refused medical insurance and become financially as well as emotionally devastated.

As you know, NIAMS was started five years ago under austere federal budget conditions. Since its inception NIAMS has been able to support a very low percentage of its approved research grant submissions compared to the other National Institutes of Health, i.e., it has not reached financial parity with the other institutes. Therefore, it is more difficult for researchers to receive grants through this institute than any of the others.

As the spokesperson for people with Marfan syndrome and other heritable disorders of connective tissue, I urge this committee to adopt the funding for the National Institutes of Health and the National Institute of Arthritis, Musculoskeletal, and Skin Diseases (NIAMS) as supported by the Coalition for Health Funding. The proposed level of funding, if adopted by the Congress, will enable NIAMS to further its efforts in the area of basic and clinical research and will also enable the Institute to promote its vitally needed training grant program. Thank you.

Senator HARKIN. $5 million for?

Ms. CICCARIELLO. For heritable disorders of connective tissue. We did not identify that in our testimony, but we do want NIH funding. Through your efforts last year, the National Institute, NIAMS, is funding a consensus, scientific research workshop April 9 to 12, and we would like to have funding to follow through on their recommendations for heritable disorders of connective tissue.

Senator HARKIN. That is amazing. You say—how many children do you have?

Ms. KIEFER. I have three.

Senator HARKIN. And they all have Marfan?

Ms. KIEFER. Yes; they do. This is a picture of my son. This was taken 2 weeks before he had his aneurysm. It was emergency surgery. This is his wife and two young daughters. He is a handsome-looking young man.

Senator HARKIN. He sure is. Now, do his children have Marfan syndrome?

Ms. KIEFER. At this present time, these two little girls show no signs of it. My daughter, my oldest daughter, her one daughter shows signs of it; and our youngest daughter, whose little kids are 4 and 1½, both show signs of it. It was devastating.

Senator HARKIN. What can they do at an early age? Is there anything they can do? I do not know.

Ms. CICCARIELLO. They do have beta blockers as treatment which can, hopefully—they hope that it will retard the enlargement of the aorta group, which is the major life-threatening aspect of Marfan, but it is also very severely handicapping orthopedically and opthamologically, because of the weakness in the connective tissue which is throughout the entire body.

Ms. KIEFER. My husband has had two—a neck hernia and groin hernia, two collapsed lungs, all with the same doctor who never, ever connected that may be being with Marfan.

We need a marker so that we can determine. My husband and two daughters are on beta blockers. The grandchildren, they are going to monitor them real closely for right now, until something else comes along.

Senator HARKIN. I know Dr. Phillips. He is good.

Ms. KIEFER. He is excellent. He is very, very good. We had a meeting with him 2 weeks ago. He is a marvelous man. And Dr. Zeff is the one who did the actual surgery, and he is a beautiful person.

Ms. CICCARIELLO. I just wanted to mention, you mentioned the genome project, and I do feel if the goals or the primary objective of the genome project would be to identify defective genes, prior to the well genes. In other words, if their focus could be on defective genes within the genome project, at the same time developing this mapping, it could kill two birds with one stone. It could accomplish finding these rare disorders which are not really getting proper funding and still be mapping the genome project.

Senator HARKIN. I can only assume that is part of the project. Do you know who is heading that project?

Ms. CICCARIELLO. Dr. Watson of Cold Spring Harbor. And I know that there are researchers who are applying the funds to map or to identify those chromosomes and genes within these defective disorders and particularly heritable disorders.

Senator HARKIN. If you begin by locating them, then you had better know how to block them in people and what drugs should be developed.

Ms. KIEFER. Yes; we had never heard of this until October 30 when Dr. Zeff came out and said it is Marfan syndrome. We never, ever had any inkling of anything.

Senator HARKIN. I am not even too familiar myself with what Marfan's is. It is an aortic——

Ms. CICCARIELLO. It is a connective tissue disorder, heritable, which means that it can be inherited, but there is also, the general population is at risk, 1 in 100,000, to have spontaneous mutation at the time of conception, so it is a disorder that does affect everybody. Abraham Lincoln, Paganini, and Rachmaninoff are supposed to maybe have had Marfan syndrome, our celebrities.

Senator HARKIN. I had heard of it before, but I never really knew what it was. I really did not know how it manifested itself.

Ms. KIEFER. Until you have heard of it, you never even hardly give it a thought. And then, when it affects your family, it is amazing.

Ms. CICCARIELLO. It does devastate families because of the inherited factor in it.

Senator HARKIN. Well, Beverly, thank you very much for coming here.

## STATEMENT OF DAVID ROBERTS, UNIVERSITY OF MISSOURI, ON BEHALF OF THE ASSOCIATION FOR EDUCATION OF REHABILITATION FACILITY PERSONNEL

Senator HARKIN. Next is Dr. David Roberts, University of Missouri on behalf of the Association for Education of Rehabilitation Facility Personnel. That is a mouth full.

Dr. ROBERTS. It is. Our own membership, sometimes, has trouble with that.

I would first of all like to sincerely thank you for your advocacy and genuine concern for persons with disabilities and the programs that serve them. Your reputation is really tremendous, and we sure hope we can keep you. It seems like the last 5 or 6 years we have lost some of our best advocates. But we are sure you will prevail. [Laughter.]

We are responsible for the preparation, maintenance, and upgrading of the skills of personnel at more than 7,000 rehabilitation facilities and community-based services. And to be very brief, the increased expectations of persons with disabilities and individuals that are caretakers and service providers have increased tremendously, both with integration into their communities, into employment. And we have to admit that we are not always as skilled, as updated as we could be.

The rehabilitation training funds, under the act, are right now at about $31 million. That is less than 2 percent of the $1.5 billion in the program. We are still at the same funding level we were at in 1979.

Senator HARKIN. Amazing. Yes; I see here in 1991, that is right, $31.1.

Dr. **Roberts**. And that is it. It is—part of the reason, and this is not in the testimony, there has been quite a bit of controversy and infighting during the last 8 years. Training, in general, is something that is easy to leave. We do not really have a natural constituency. The needs that——

### PREPARED STATEMENT

I personally am both a counselor/educator and also a continuing educator, and I serve the States of Missouri, Iowa, Kansas, and Nebraska. And we have about $300,000 to serve over 4,000 personnel, and we just, frankly, just do not have the resources that we need, and we are asking you—the authorization level was $38 million, and to somehow get back to at least the level of 1979 would be helpful.

Thank you very, very much.

[The statement follows:]

## STATEMENT OF RONALD B. HOUSE, PRESIDENT, ASSOCIATION FOR EDUCATION OF REHABILITATION FACILITY PERSONNEL

**Mr. Chairman, there is an erosion undermining the knowledge and skill level of professionals serving persons with disabilities that threatens the entire fabric of our service delivery system of rehabilitation facilities and programs.**

**Once again the Administration has requested level funding for rehabilitation personnel training under the Rehabilitation Act of 1973. That is essentially the same level of funding as in 1978, thirteen years ago!** Budget documents from the Department of Education state that, "...available data on personnel shortages do not support appropriations increases." The problem is that the Administration continues to ignore the data that they have gathered in the past and they have not done the major descriptive needs study mandated by Congress in the Rehabilitation Act that would verify the needs that we all know exist. Sec. 304(c) of the Rehabilitation Act requires RSA submit to Congress "...a report setting forth and justifying in detail how the training funds for the fiscal year prior to such submission are allocated by professional discipline and other program areas. The report shall also contain findings on personnel shortages...and how the findings of personnel shortages justify the allocations..."

Mr. Chairman, my name is Ron House. I am president of the Association for Educatoion of Rehabilitation Facility Personnel (AERFP). This association represents 18 universities, colleges, and professional organizations that provide continuing education and training to the personnel of over 5000 community based organizations that provide a variety of services for persons with disabilities. These organizations include rehabilitation facilities, supported employment programs, and independent living centers.

I am here today to request that adequate funds be appropriated to enable us to respond to the ever greater training needs of the programs we serve. The attached chart graphically illustrates the sad state of funding for rehabilitation personnel training. The request of the Administration for level funding of $31.1

million would be almost $7.5 million short of the authorized under Section 304 of the Rehabilitation Act of 1973. We believe that even full funding would not be nearly enough to meet the current training needs but it would at least reverse the trend of minimal increases over the past several years. **We urge this subcommittee to appropriate the full authorized level of $38.5 million for FY 1991.**

Rehabilitation programs require staff who are well prepared, skilled, and sensitive to the diverse challenging needs of persons with disabilities. 65,000 employees in over 4,000 rehabilitation facilities provide services to over one million persons with disabilities each year. A 1989 study on staff turnover in rehabilitation facilities indicated that turnover among facility staff may be as high as 24% a year. Another recent study reports that job coaches stay on the job only 14 months. Such turnover disrupts services to persons with disabilities, staff morale, and productivity.

**The educators of community-based program personnel are a vital link in the integration of persons with disabilities into the work force of our nation.**There are new initiatives such as supported employment which desperately need trained professionals to insure quality programs that will have long term success. **The anticipated passage of the Americans With Disabilities Act will increase the need for professional who can train and place persons with disabilities into community jobs.**These new programs will place ever increasing demands on rehabilitation facilities and other service providers. The erosion in the foundation of trained professionals endangers these new initiatives.

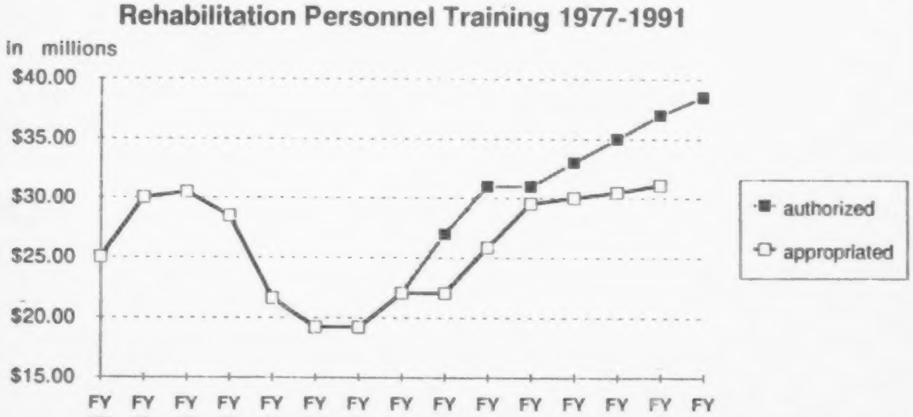
**AERFP recommends that regional rehabilitation facility administration continuing education programs be created as the single primary facility personnel training resource for each region.** This new program would administer technical assistance and post-employment personnel training related to community supported employment and other facility administered vocational programs. This new training grant would consolidate several current grant programs thereby reducing the overall number of grants.

and the accompanying overhead and administrative costs. Most importantly, these regional grants would provide for continuity of training services that has not previously been available. AERFP urges this subcommittee to recommend these new regional facility training grants in its report.

Training rehabilitation professionals is but a part a much larger process. AERFP supports all of the other parts of the Rehabilitation Act. We urge full funding of basic state grants and supported employment to insure that the services are available to as many persons with severe disabilities as possible.

**In summary, Mr. Chairman, we urge the subcommittee to recommend full funding of $38.517 million for fiscal year 1991 and include report language urging the development of regional training grants for rehabilitation facility administration.**

Thank you very much for this opportunity to present this testimony. I will be glad to answer any questions you may have.



Source: U.S. Budget Documents

Senator HARKIN. You mean the level with inflation?

Dr. ROBERTS. No; we were funded at $30 million in 1979, and we are now funded at $31 million in 1990.

Senator HARKIN. Maybe I just missed something. I was looking for something else here. You say you want to get back to the funding of 1979.

Dr. ROBERTS. Well, in 1979, we were funded at $30 million. We have just now gotten back to $31 million total, and we are asking for full funding, which is $38 million.

Senator HARKIN. OK, thank you.

David, tell me, what is the difference between your organization and the National Council on Rehabilitation Education that we just heard from Dr. Dew.

Dr. **Roberts**. The national council primarily represents what we would call preservice, that is university-based, degree-granting programs. My organization represents people who are already employed, working in rehabilitation facilities in their communities.

Senator **Harkin**. The other one is basically those that are just being educated? The educators.

Dr. **Roberts**. Predominantly. But both of us are in the same, at this time, $31 million.

Senator **Harkin**. And the National Rehabilitation Association?

Dr. **Roberts**. Is the general organization representing professionals across the board in all rehabilitation.

Senator **Harkin**. I just want to make sure I understand just who you are talking about here, but you are all basically, are asking for the $38 million, yeah, $38.5 for rehabilitation training. I just want to make sure I knew how these are all together here.

Well, thank you very much. Thank you for your kind words.

## STATEMENT OF LAWRENCE MELI, COCHAIRMAN, COUNCIL OF ORGANIZATIONAL REPRESENTATIVES

Senator **Harkin**. Next is Lawrence Meli, Council of Organizational Representatives.

Mr. **Meli**. Thank you. Good afternoon. My name is Lawrence Meli, and I am cochairman of the Council of Organizational Representatives, which is a group of 15 national, regional, and local groups dedicated to sharing ideas and working together to assist all Americans with a hearing loss. A list of those organizations and membership, or friends of, is provided in my written testimony.

For your information, I would also like to mention that I am a board member of the Deafness Research Foundation, the Alexander Graham Bell Association for the Deaf, and the National Institute on Deafness and Other Communication Disorders.

With millions of Americans affected by hearing loss, the total number must be multiplied by at least two, if not four. Clearly, in this country today, it could be estimated that because a person with a hearing impairment has a mother or father, wife or husband, son or daughter, brother or sister, and friends, that close to 100 million Americans are affected directly or indirectly by hearing loss.

As the parent of a hearing-impaired son, I know firsthand how the difficulty of communication has had an enormous impact on my family. The quality of life for my son and millions of others is by no means what it could and should be.

With the creation of the National Institute on Deafness and Other Communication Disorders, now for the first time there is hope and promise that research will provide breakthroughs in understanding the ear and its workings, as well as improve upon the lifestyles of people with a hearing loss and someday provide the complete restoration of hearing.

There is so much optimism that the NIDCD will lead the way in not only providing answers and treatments, but to act as the nucleus and clearinghouse for all information related to hearing loss.

One cannot imagine the frustration one experiences living in the greatest country on Earth and having to search frantically for information and guidance, when you learn that a loved one has a hearing loss.

Some of the activities of the Institute that hold a good deal of promise are research into the genetics of hearing loss, improvement of hearing aids, cochlear implants, tactile aids, development of a vaccine for the otitis media, develop more effective, rehabilitative strategies for the treatment of hearing loss in children and the elderly and with special attention on the educational needs of the prelingual deaf, to conduct clinical research to develop an effective treatment of tinnitus, develop assistive devices for communication and establish a program to identify hearing loss in all children in the United States by the age of 9 months.

At the Council of Organizational Representatives, many different groups come together each month to share and exchange information and provide direction to our coalition. It may be hard to believe, but a more divergent group would be difficult to find. From research to medical associations, to those that believe in sign language as the primary way to communicate, to those that believe in oral communication, from cued speech groups to telecommunications groups, we all meet monthly. Our group represents over 100,000 members with the desire to assist those with a hearing loss.

It is most challenging to have the membership of the council agree on everything, but there is one item that was endorsed unanimously, and that is our recommendation that the budget allocated the Institute in fiscal year 1991 be $165 million.

## PREPARED STATEMENT

Thanks to you, Senator, this money will be used to build the Institute from the sound foundation that was created with the passage of the bill that created the Institute. I thank you for initially recognizing this national need and ask that you support the Institute in a fashion that will allow for that foundation to be adequately built upon. Thank you.

Senator HARKIN. Thank you very much. Well, we got it up to $117 last year, so we will see what we can do this year. You know of my intense interest in this area, and hopefully, we can get that far or get as close as possible. We will do our best.

Mr. MELI. Thank you, Senator, and on behalf of CORE and all the other groups that I represent, I want to express our gratitude to you for your help in this area. Thank you.

[The statement follows:]

# STATEMENT OF LAWRENCE MELI, COCHAIRMAN, COUNCIL OF ORGANIZATIONAL REPRESENTATIVES

Good morning. My name is Lawrence Meli and I am co-Chairman of the Council of Organizational Representatives which is a group of 15 national, regional and local groups dedicated to sharing ideas and working together to assist all Americans with a hearing loss. A list of those organizations and membership or friends of is provided in my written testimony.

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There is so much optimism that the N.I.D.C.D. will lead the way in not only providing answers and treatments but to act as the nucleus and clearinghouse for all information related to hearing loss. One cannot imagine the frustration one experiences living in the greatest country on earth and having to search frantically for information and guidance when you learn that a loved one has a hearing loss.

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## THE COUNCIL OF ORGANIZATIONAL REPRESENTATIVES

Alexander Graham Bell Association for the Deaf
American Academy of Otolaryngology - Head and Neck Surgery
American Deafness and Rehabilitation Association
American Society for Deaf Children
American Tinnitus Association
Conference of Educational Administrators Serving the Deaf
Convention of American Instructors of the Deaf
Deafness Research Foundation
Ear Foundation
National Association of the Deaf
National Cued Speech Association
New York League for the Hard of Hearing
Self Help for Hard of Hearing People
Telecommunications for the Deaf, Inc.

## CORPORATE MEMBERSHIP

Corporate Services for the Deaf, Inc.

## C.O.R. HISTORY

In 1980, Dr. T. Alan Hurwitz and Dr. William Castle became presidents-elect for the National Association of the Deaf (NAD) and the Alexander Graham Bell Association for the Deaf (AGBAD), respectively. During the two years that followed they conferred with one another with some frequency about the ways in which the two organizations might work more closely together and enlist the interest of other organizations of and for the deaf to do the same.

On June 25, 1982, when Dr. Castle presented his inaugural speech at the Toronto convention of AGBAD, the speech was entitled "Working Together/Tous Ensemble; Building Networks for Progress." Within that speech it was pointed out that "...The Alexander Graham Bell Association for the Deaf does not exist in a vacuum; it is an organization among organizations, all of which serve the interest of deaf people... All such organizations and agencies exist because they stand for different and special purposes; and some of the differences of course, are philosophical. However, differences in philosophy need not disappear in order for them to become less of an obstacle to cooperation among organizations."

In early July of 1982, at the NAD convention in St. Louis, Missouri, Dr. Hurwitz presented his inaugural speech, which was entitled "Reflections: Past, Present, and Future Outlook." Within that speech Dr. Hurwitz said "...We must develop stronger working relationships with other national organizations which serve the needs of deaf people and other disabled people. We cannot afford to function alone. Our number is too small to have sufficient clout on political and legislative matters. Government officials tend to shy away from us when there is infighting among us. We have more to lose by splitting among ourselves. True, we have differences and are unique in our own ways, but there is a great deal of common ground for all of us to work together."

What followed in 1982 was a special mini-conference which had as its theme "Working Together on Legislative Goals Regarding Deafness." The organizations involved in the meeting in addition to the National Association for the Deaf and the A.G. Bell Association for the Deaf were the executive directors of the American Deafness & Rehabilitation Association, the Convention of American Instructors of the Deaf, the American Society for Deaf Children, the Registry of Interpreters for the Deaf, and Telecommunications for the Deaf, Inc.

The mini-conference was held on the campus of Gallaudet College on January 14-15, 1983. All the participants came at their own expense or at the expense of their organizations. Fifty-four people were invited and forty-three actually did attend.

The conferees voted unanimously for some kind of legislative coalition to be put in place. This Council of Organizational Representatives has been meeting regularly on a monthly basis since the first meeting in February 1983. Its agenda has been very diverse but always on target; and very recently the number of member organizations has increased as we move to make the organization more formal and proactive rather than reactive.

## STATEMENT OF JULIAN D. STREETT, COMMUNITY PROVIDERS ASSOCIATION, INC.

Senator **Harkin**. Next is Julian Streett, Community Providers Association of Little Rock, AR, on behalf of the National Association of Private Residential Resources.

Mr. **Streett**. Senator, we appreciate this opportunity to be here, and we also would like to express our appreciation to you and other Members of Congress for assistance that we got last year in the Budget Reconciliation Act process, and I would like to give you a little bit of background and would just emphasis two of the things that are covered in my written remarks.

In this last year, HCFA has set out to eliminate funding through Medicaid for community services to the developmentally disabled unless they are in a ICFMR facility or unless they are funded under the waiver. What this means is that individuals who do not reach the threshold of being at risk of going into an institution can no longer receive services in the community that are funded through Medicaid.

To give you two examples of what this has meant in Arkansas, we have had an extremely successful pilot program in several areas of the State in which, in early intervention services, we have taken individuals into the home to work with family members to try to ameliorate the problems that exist with these very small children, and we have discovered that we are reducing, significantly, the lifelong impact that the disability has by going into the residence and being able to do this.

We now find that this type of community habilitative service, that HCFA has administratively sought to eliminate it, and did, in fact, eliminate it in the State of Maine and put the State of Arkansas on notice that it would be eliminated.

Due to language that was included in the budget reconciliation process, HCFA was told that they could not use the guise of saying that, because we were seeking to habilitate people that were developmentally disabled, that was not included under the definition of rehabilitation and, therefore, even though we might be able to go into the home and provide home health care to change a child's diaper, an adult's diaper that has toilet problems or the different types of services, even though we might be able to provide the mental health type treatment in the residence, we could not go into the home and provide the developmental disability training that is necessary to end that condition.

So, we would ask you to be aware that HCFA now is in the process of promulgating regulations, and if those regulations come down with the same impact that their past intentions indicate, we are going to be back before Congress asking for some definition in the Medicaid Act that would define treatment for the developmentally disabled as a covered service under Medicaid.

The two things, specifically, that I would like to mention that deal with the appropriation process, one of them deals with the funding under Public Law 94-142. At the time that act was first implemented, there was a promise made that the Federal Government essentially would fund 40 percent of the cost of that program. The current increased funding recommended by the President will rise only to 9 percent of the total cost of that program per student, and the Coalition for Citizens With Disabilities has requested that that level be raised to 20 percent.

I would point out to you, specifically, that under Public Law 99-457, as we mandate down now the Educational Handicap Act age of coverage to the age of 3, we are imposing significant, new requirements on the States in terms of cost. In the State of Arkansas, we have added about 7 or 8 percent to the total number of children that we have to serve in the public schools with no increase in Federal funding, other than the grant dollars under Public Law 99-457.

The second thing I would ask you to give serious consideration to is the increase in funding that came through the House process last year for Medicaid reform under Representative Waxman's bill. And there was a request that got through to the House, from the House side to the Senate side, for $40 million in increased funding for Medicaid benefits for individuals that are developmentally disabled, and I expect that that will come forward again, at this point.

Senator Chafee's bill never had an accurate cost figure attached to it, but we would urge you to do that because again, what we are discovering is that these dollars that are spent for the developmentally disabled, truly reduce—if spent at an early age—the dependency, the lifelong dependency, and those dollars that are spent once the children exit the public school system, we discover that if we are able to maintain them when rehab has done the training and then provide the minimal level of assistance for many of them in their job-supported activities, that they can function independently.

But with the inability to use the Medicaid dollar to provide those continued types of support services, the habilitative training that is necessary, we find that many people cannot maintain themselves in an independent living environment, cannot retain their job.

So this idea of increasing funding for habilitative services with developmental disabled is extremely important.

Senator **Harkin**. Tell me again, what is Medicaid's reasoning why they cannot use that money for that?

Mr. **Streett**. There are two options under the Medicaid Act for funding individuals outside of the ICFMR or the Waiver Program. Those are the clinic program, where you actually serve somebody in what is the equivalent of a medical clinic, or under the rehabilitative services option. In Arkansas, for 8 years now, we have served people under the clinic option; we have attempted to add services under the rehabilitative services option. What HCFA has done is taken a very narrow interpretation of this language, and said because the Medicaid Act specifically mentions habilitative services in the ICFMR program and does not mention habilitative services as a separate area that can be covered under Medicaid, since we are not rehabilitating an individual, as you would be in some types of mental illness, as you would be in the type of physical injury—we are attempting to habilitate and acquire a skill that has never been there— that were not covered.

### PREPARED STATEMENT

And I do not think that was the intent of Congress when they wrote the Medicaid Act. I think it is a narrow, legalistic approach, that is a budget-cutting type of thing that has come out of HCFA, and we were successful in getting the language and budget reconciliation that told HCFA they could not do this until they at least defined what habilitative services was and went through that process. But if they go through that process and now define what is covered under Medicaid to exclude the community-based instruction, we are back to the anomaly of not being able to teach people out in the community to ride a bus, or to go into the home for people with infants and to give them the training that will reduce the extent of the disability because we have no funding source, other than pure State dollars. We cannot use Medicaid to do those types of things.

Senator HARKIN. Mr. Streett, thank you very much.

[The statement follows:]

# STATEMENT OF JULIAN D. STREETT, COMMUNITY PROVIDERS ASSOCIATION, INC., ON BEHALF OF THE NATIONAL ASSOCIATION OF PRIVATE RESIDENTIAL RESOURCES

The National Association of Private Residential Resources currently represents more than 500 agencies in 48 states and the District of Columbia that together provide residential services to more than 40,000 people with mental retardation and other developmental disabilities. Our members offer a full range of residential services in a variety of settings designed to enhance the development and self-dependence of those served. Most NAPRR members serve people at more than one site. Funding for residential services varies from state to state and agency to agency. A number of federal funding sources are under the jurisdiction of this Subcommittee. For purposes of this testimony, NAPRR has chosen to focus on the following programs because they provide significant support for residential services.

## MEDICAID

It is estimated that about 800,000 people with developmental disabilities currently receive Title XIX Medicaid benefits. Thousands of these individuals with severe mental and physical disabilities receive Medicaid assistance for long-term residential services in intermediate care facilities for the mentally retarded (ICFs/MR) and nursing facilities. Others receive assistance for residential and/or daily program services through their state's Medicaid Waiver for Home and Community Based Services, or optional state services identified in their State Medicaid Plan.

### Clinical and Rehabilitation Services

Last year at this time, approximately 40 percent of the states were threatened with the loss of Medicaid reimbursement for habilitation services funded within the state's definition of clinic or rehabilitation services. NAPRRwould like to take this opportunity to thank members of this Subcommittee forsupporting reconciliation language passed last year that prevents the Secretary of the Department of Health and Human Services from discontinuing federal financial participation for these programs without rules to define services that may be provided under a state plan. This year we urge your support for federal rules that will permit the continuation of programs already being funded.

NAPRR THEREFORE URGES THE INCLUSION OF LANGUAGE IN THE FY 1991 APPROPRIATIONS ACT TO DIRECT THE ADMINISTRATION TO DEVELOP RULES THAT WILL PERMIT THE CONTINUED REIMBURSEMENT OF HABILITATION SERVICES IN THE COMMUNITY FOR PEOPLE WITH MENTAL RETARDATION AND RELATED CONDITIONS WITHIN STATE MEDICAID PLAN PROVISIONS FOR CLINICAL OR REHABILITATION SERVICES.

### Equitable Reimbursement

When intervening forces such as the new ICF/MR rules adopted in 1988, and mandatory wage increases imposed by federal law beginning April 1 of this year, etc., are applied to Medicaid programs, reimbursement levels must increase to adequately address the new requirements. Because private providers in most states experience discriminatory treatment within state reimbursement systems, the impact on the private sector is particularly onerous when the costs of compliance increase. Medicaid law, Section 1902(a)(13)(A), requires states to provide reimbursement levels that are "reasonable and adequate to meet the costs which must be incurred by efficiently and economically operated facilities in order to provide care and services in conformity with applicable State and Federal laws, regulations, and quality and safety standards." In actual practice, however, reimbursement levels in many states make it impossible for even the most efficiently and economically operated private facilities to comply with mandated requirements. The most obvious effect of the disparity between public and private sector reimbursement is in the wages and benefits provided to staff and the resulting impact on the quality of services. Although states are providing the Administration with assurances that they are complying with this provision of the statute, little attention is given to actual state reimbursement practices. Federal money is supporting services in both privately- and publicly-operated facilities. Individuals served by the private sector have a right to be treated more equitably, wherever they are served.

TO PROMOTE EQUAL TREATMENT AND ENCOURAGE QUALITY SERVICES IN BOTH THE PRIVATE AND PUBLIC SECTORS, NAPRR ASKS THIS SUBCOMMITTEE TO EXAMINE IMPLEMENTATION OF SECTION 1902(a)(13)(A) AND STATE ASSURRANCES THAT THEY ARE CONFORMING TO THAT AMENDMENT BY PROVIDING REIMBURSEMENT LEVELS THAT ARE "REASONABLE AND ADEQUATE TO MEET THE COSTS WHICH MUST BE INCURRED BY EFFICIENTLY AND ECONOMICALLY OPERATED FACILITIES IN ORDER TO PROVIDE CARE AND SERVICES IN

CONFORMITY WITH APPLICABLE STATE AND FEDERAL LAWS, REGULATIONS, AND QUALITY AND SAFETY STANDARDS," AND ASSURE THAT THIS IS, IN FACT, OCCURRING.

NAPRR ALSO REQUESTS THE ADDITION OF LANGUAGE THAT WILL REQUIRE STATES TO USE REIMBURSEMENT METHODOLOGIES WHICH WILL NOT DISTINGUISH BETWEEN STATE-OPERATED PROVIDERS AND OTHER PROVIDERS.

### Community Habilitation Services

Bills have been introduced in Congress to expand the services that can be reimbursed by Medicaid. Of particular interest to NAPRR is legislation that would permit Medicaid reimbursement of a state program of habilitation services for people living at home or in community living arrangements. Without passage of such legislation, states will be increasing their dependence on the ICF/MR program which has been found to be a more costly method of service delivery.

NAPRR STRONGLY SUPPORTS THE ADDITION OF $40 MILLION TO THE MEDICAID BUDGET AUTHORITY IN FY 1991 TO SUPPORT IMPORTANT EXPANSION OF MEDICAID ENTITLEMENTS TO COVER COSTS ASSOCIATED WITH INCREASED COMMUNITY HABILITATION SERVICES.

### Medicaid User Fees

This year the President's Budget proposes financing Medicaid facility surveys through "user fees" charged to the facilities themselves. As stated earlier, Medicaid statute currently requires that reimbursement be adequate to permit all providers to meet costs associated with serving eligible recipients. If the fees are not reimbursable, we can expect Medicaid providers to close their programs, leaving thousands of people unserved. Most providers in the field of mental retardation have no means through which to cover the costs of such fees, and collecting them from the people served is both illogical and illegal. Added to the costs of reimbursement for Medicaid services, user fees would also increase current costs of the surveys by the addition of new administrative costs associated with collecting and disbursing the money. It seems inappropriate to add any new, unnecessary costs for any sector of the Medicaid program.

NAPRR URGES THIS SUBCOMMITTEE TO REJECT THE PRESIDENT'S PROPOSAL TO COLLECT "USER FEES" FROM MEDICAID PROVIDERS TO PAY COSTS ASSOCIATED WITH SURVEYS.

## SOCIAL SECURITY DISABILITY INSURANCE AND SUPPLEMENTAL SECURITY INCOME

The Social Security Disability Insurance Program (SSDI) provides monthly cash benefits to over 4.1 million workers under age 65 who are no longer able to engage in "substantial gainful activity (SGA)." The Supplemental Security Income (SSI) program makes monthly cash payments to 4.2 million low-income people who are aged, blind or disabled. In FY 1990 an estimated 3 million people with disabilities will receive SSI benefits (more than 70 percent of the total who receive SSI). NAPRR is supporting legislation being considered by Congress that will:

1) encourage SSDI beneficiaries to return to work by gradually reducing the level of their benefits as their earnings increase, rather than discontinuing them as soon as work commences;
2) make permanent the provision expiring at the end of 1990 that continues payment of social security benefits during appeal of benefit termina
3) increase the definition of SGA to the same level as that for a person who is blind; and
4) gradually increase SSI benefits to the poverty level.

NAPRR also supports an improvement in standards used to determine eligibility of children; and we oppose the Administration's proposal to charge states a fee for administering their SSI supplementation programs.

NAPRR JOINS OTHER DISABILITY ADVOCATES IN SUPPORTING ADDITIONAL APPROPRIATIONS TO INCREASE WORK INCENTIVES FOR THOSE WHO RECEIVE SSDI; PERMIT THE CONTINUED PAYMENT OF BENEFITS DURING APPEAL; INCREASE THE DEFINITION OF SGA TO THE LEVEL PROVIDED TO PEOPLE WHO ARE BLIND; INCREASE SUPPLEMENTAL SECURITY INCOME BENEFIT LEVELS; AND IMPROVE ELIGIBILITY DETERMINATIONS FOR CHILDREN. NAPRR FURTHER RESPECTFULLY ASKS THIS COMMITTEE TO REJECT THE PRESIDENT'S PROPOSAL TO COLLECT FEES FROM STATES FOR THE ADMINISTRATION OF THEIR SSI SUPPLEMENTATION PROGRAMS.

## OTHER HHS PROGRAMS

NAPRR ALSO SUPPORTS ADDITIONAL APPROPRIATION REQUESTS INCLUDED IN THE BUDGET ANALYSIS DOCUMENT PRESENTED TO THIS COMMITTEE BY THE CONSORTIUM FOR CITIZENS WITH DISABILITIES. Included with these are the following:

| Program | FY 1990 Appropriations | FY 1991 CCD Recommendation |
|---|---|---|
| | (in millions) | |
| o Title XX Block Grant | $2,762.0 | $3,300.0 |
| o Voc. Rehabilitation State Grant | 1,528.5 | 1,875.5 |
| o Supported Employment State Grant | 27.6 | 31.0 |
| o State Services for Independent Living | 12.94 | 14.43 |
| o Centers for Independent Living | 26.67 | 30.17 |
| o P.L. 94-142 State Grants | 1,542.6 | 3,493.0 |
| o DD Basic State Grant | 61.9 | 81.27 |
| o DD Special Projects | 2.4 | 3.9 |

## STATEMENT OF JOHN FOLKINS, PROFESSOR, UNIVERSITY OF IOWA, ON BEHALF OF THE AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION

Senator HARKIN. Next is Professor John Folkins, University of Iowa.

Dr. FOLKINS. Mr. Chairman, it is an honor to appear before this appropriations subcommittee on behalf of the American Speech-Language-Hearing Association, ASHA.

ASHA is the national professional and scientific association for over 60,000 speech language pathologists and audiologists serving the needs of children, adults, and senior citizens who have communication disorders. The testimony today will focus on the funding needs for fiscal year 1991 for the National Institute on Deafness and Other Communication Disorders, NIDCD.

The creation of the NIDCD has given us an historic opportunity, and the environment for expanding research in communication disorders is really very favorable at this time. Such an expansion is needed because of the great many areas of need. Some of those areas we have heard about today, the areas are summarized in a 350-page document that is the national strategic research plan. I was one of the scientists involved in developing that plan. We do not need to go through 350 pages here today. I just wanted to point out a couple of them that I think need to be mentioned or thought about again. Multicultural research in communication disorders, prevention of communication disorders, outcome and treatment efficacy studies for communication disorders, applications of existing technology and communication disorders. Application—one of the things that NIDCD is concerned with is development of synthetic speech. Synthetic speech can be used to help communication with the blind, as we had heard earlier today here.

Also, I want to point out that some of the communication disorders with some of the very high prevalence are communication disorders related to speech, voice, and language. Voice disorders prevalence are at 3 percent, which is a very high prevalence and even higher than that in children. Language and speech are also high.

Language is related to literacy that we have heard about today. So much of this all ties together.

In addition, there is a critical shortage of the scientists with the training to carry out the needed research. As you know, many of us who offer research training in communication disorders are preparing for growth in training opportunities. However, we need to be able to offer training stipends to beginning researchers or they are going to head for opportunities that do offer them support.

Expectations are high that Congress will demonstrate its commitment to growth and communication disorders research through increased funding for research training. Expansion in research training is fundamental to the long-term success of NIDCD.

The request for proposals for national research and training centers that was issued in December 1989, has generated a tremendous amount of attention, excitement, and discussion among researchers. I have heard that approximately 20 proposals were submitted for the national research and training centers. There are funds to support three, possibly four, of these centers. Clearly, there is a great need to continue to develop the interdisciplinary collaboration and research training inherent in the concept of these centers. We just need more of them.

Personally, I have been involved in the development of two of the proposals for research in the training centers, and in that, it is clear to me that the preparation of the proposals have a number of beneficial effects in themselves. The research training, especially training for clinical researchers, receives more attention. New collaborations, channels of communication are developed. Many new research ideas come out of the proposal-writing process, and a lot of these ideas are going to end up as proposals for new research grants in the coming year.

Unfortunately, the President's budget for fiscal year 1991 would do little to meet the demands in this area of research. The President's budget request is only about 4.5 percent over the final post-sequestered fiscal year 1990 level. At this level, there would be little or no growth in research opportunities. Much of the excitement generated in the past few years would dissipate.

### PREPARED STATEMENT

We recommend that $165 million be appropriated for NIDCD in fiscal year 1991, and this recommendation is consistent with that of other organizations.

Thank you for the opportunity to testify, and we also want to say that we really do appreciate your leadership in relations to communication disorders and all individuals with disabilities.

[The statement follows:]

# STATEMENT OF JOHN FOLKINS, PROFESSOR, UNIVERSITY OF IOWA, ON BEHALF OF THE AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION

Mr. Chairman, it is an honor to appear before this Appropriations Subcommittee on behalf of the American Speech-Language-Hearing Association (ASHA). Our testimony will focus on funding needs in fiscal year 1991 for the National Institute on Deafness and Other Communication Disorders (NIDCD).

ASHA is the national professional and scientific association for over 60,000 speech-language pathologists and audiologists serving the needs of children, adults and senior citizens throughout the United States who have communication and related disorders. The ability to communicate effectively is fundamental to other life activities, e.g., learning, interpersonal relationships, vocational pursuits. A loss of or limitation of this ability can be detrimental to an individual's development, accomplishments, and overall quality of life.

Approximately 33 million Americans of all ages have some kind of communication disorder, making this the nation's most prevalent disability. It is estimated that these disorders cost the economy $30 billion a year in lost productivity, special education costs, and health care costs. These costs are expected to grow, due to several factors. First, increasing numbers of infants and small children are suffering from communication disorders. As more babies survive because of medical technological advances, there are more children with severe disabilities, often including speech, language and hearing disabilities. With higher incidences of poverty and drug abuse, there are more disadvantaged children with communication impairments. Accidents, especially involving motor vehicles and firearms, also have increased the volume of head injured and communicatively impaired individuals, especially among teenagers and young adults. Noise-related hearing loss is still another increasingly prevalent phenomenon.

Second, the frequency of communication disorders will increase dramatically as the population ages. Impairment in the ability to speak, hear, or process language is often associated with diseases and conditions that occur among adults as they get older: Alzheimer's disease, Parkinson's disease, and other progressive neurological disorders resulting in oral-motor dysfunction; stroke, resulting in aphasia; cancer of the larynx, resulting in laryngectomy; and presbycusis, or degeneration of the auditory function associated with the aging process, resulting in hearing impairment.

Many of the costs relating to these conditions are borne by the federal government and state governments. The populations targeted by research through NIDCD are the same populations which receive services through the Education of the Handicapped Act, the Rehabilitation Act, Medicare, Medicaid, Social Security Disability Income and other public programs. Research that leads to the amelioration of communication disorders through prevention and treatment should result -- in the long run -- in a reduction in need for special education, rehabilitation and other services.

The creation of the National Institute on Deafness and Other Communication Disorders (NIDCD) has given us an historic opportunity to focus research efforts on a disability area that will continue to grow well into the next century. Congress should recognize the importance of increasing funding in the area of communication disorders for several reasons.

First, there is a critical shortage of trained researchers in the field. Expectations are high that Congress will demonstrate its commitment to seeing this field grow through increased research training funding. This will encourage the brightest students now in training programs to pursue a career in this exciting area of research. There is a need for more qualified researchers from various disciplines involved with communication disorders, including speech-language pathologists, audiologists and speech-language-hearing scientists.

Second, the leadership last year of the former Acting Director, Dr. Jay Moskowitz, and the current leadership of Dr. James Snow, the Institute's first permanent director, have brought a heightened degree of awareness and excitement in communication sciences and disorders. The scope of NIDCD is very broad, encompassing a variety of disorders and a very large population. There also are numerous professional, provider, consumer and voluntary organizations representing a spectrum of philosophies and approaches in the field. Because of heightened awareness about communication disorders and greater potential for collaborative work, the environment for expanded research is extremely favorable. The opportunity for exciting multidisciplinary research has never been greater. The National Strategic

Research Plan, developed for the Institute by the most respected researchers in the field, is evidence of the collaborative work that is possible.

Third, the Institute holds great promise that some of the difficult challenges within the field of communication disorders can now be addressed. Specifically, in the area of multicultural research, there is pressing need for basic epidemiologic information on the incidence, prevalence, and risk of communication disorders within the population at large and specifically within minority populations -- i.e., Black, Hispanic, Asian, and American Indian populations; research also is needed on the relationship between communication disorders and various diseases that have a high prevalence within minority populations. In addition, research on normal hearing, hearing loss and deafness across multicultural populations is needed. For instance, otitis media, a leading cause of hearing loss in young children, occurs most frequently among American Indians and least frequently among Blacks.

The specific Congressional authorizations for the Institute to establish a data system to collect, store, analyze, retrieve and disseminate data derived from patient populations and to establish an information clearinghouse are also long overdue developments. In addition, the Senate Committee on Appropriations has recommended that priority attention be given to several areas, including: new and expanded research training programs, prevention or management of certain types of disorders, and the expanded development of technology -- hearing aids, cochlear prostheses, assistive devices, etc. -- to aid in rehabilitation of individuals with communication disorders.

Unfortunately, the President's budget for FY 1991 would do little to meet the demands of this area of research. The President's budget request of $122.95 million represents an increase of about 4.5 percent over the final (post-sequester) FY 1990 level. At this level, there would be little or no growth in the variety of research opportunities, and much of the excitement generated in the past two years would be drained.

Dr. Snow has testified before this Subcommittee about the need for research initiatives in various areas, including: neurobiology and auditory research, causes and potential remedies for hereditary deafness and otitis media. He also discussed plans for research training, continuing education for health professionals, multidisciplinary research efforts, and information dissemination.

While these are all important needs, they address only a portion of the needs of persons with communication impairments. Persons with speech, voice, and/or language impairments also require attention. Research is needed to identify what treatment regimes are efficacious, effective, and the most efficient. For example, because of surgical intervention for oral and laryngeal cancer, many Americans require rehabilitation to return to being effective communicators. What are the methods of choice? Language impairments in young children can affect their ability to experience success in school, because of both the potential academic and social ramifications of such disorders. How are these problems best addressed? Stroke, as the third leading cause of death in the United States continues to leave many adult persons with aphasia, difficulty in processing and producing language. How to obtain the best quality of communication, and consequently life, is of great concern.

The opportunities and challenges for research to uncover causes of communication disorders and to develop modes of treatment and prevention are especially relevant as we embark on the Decade of the Brain. However, ASHA is concerned that these goals and plans cannot be achieved without a significant increase in funding next year.

We recommend that $165 million be appropriated for the National Institute on Deafness and Other Communication Disorders in FY 1991. This recommendation is consistent with that of other organizations and coalitions, including the Friends of NIDCD and the Consortium for Citizens With Disabilities.

Senator Harkin, we appreciate this opportunity to testify and express our continuing appreciation to you for your outstanding leadership on policies benefiting persons with communication disorders and other disabilities.

Senator **HARKIN**. Let me thank you and your colleagues for all your work in this area, too, for so many years. You have worked at the University of Iowa for what, 13 years?

Dr. **FOLKINS**. Yes; I have been there for 13 years.

Senator **HARKIN**. As I have said to others, I am going to see how close we can get to $165 as possible.

Dr. **FOLKINS**. There are certainly so many needs, as I have tried to outline, we could—we need training in the centers, research needs, they are all there.

Senator **Harkin**. It is just that this is one area that has been ignored for a long time, and we are trying to play a little catch up ball here.

Dr. **Folkins**. Thank you.

Senator **Harkin**. Thank you very much, Dr. Folkins.

## STATEMENT OF DOROTHY L. GORDON, ON BEHALF OF THE AMERICAN CONGRESS OF REHABILITATION MEDICINE, THE AMERICAN ACADEMY OF PHYSICAL MEDICINE AND REHABILITATION, THE ASSOCIATION OF ACADEMIC PHYSIATRISTS

Senator **Harkin**. And next is Dr. Dorothy Gordon, Johns Hopkins School of Nursing, here for the American Congress of Rehabilitation Medicine, the American Academy of Physical Medicine and Rehabilitation, and the Association of Academic Physiatrists. I thought that said psychiatrists, without the C. Physiatrists, that is right.

Dr. **Gordon**. Some people confuse it, but it is physiatrist, a medical specialist in physical medicine and rehabilitation.

Senator **Harkin**. Very good. Well, welcome to the subcommittee.

Dr. **Gordon**. Thank you, Mr. Chairman.

As you know, my name is Dorothy Gordon and I hold a doctorate in nursing sciences, and I am on the faculty of the Johns Hopkins University.

Senator **Harkin**. Do you know Dr. Strachota back here?

Dr. **Gordon**. No.

Senator **Harkin**. Well, you had better meet each other before you leave. [Laughter.]

Dr. **Gordon**. I saw her name on the list, and I was going to wait. We will talk.

I am also president of the American Congress of Rehabilitation Medicine, which is an interdisciplinary professional organization of over 3,000 nurses, physicians, physical therapists, social workers, psychologists, and other health workers who work in a team process to deliver rehabilitation services.

The case mix of clients that we serve and are concerned with are those with severe disabilities, such as spinal cord injuries, head injuries, stroke, multiple sclerosis, and others. And as you know I am testifying also in behalf of the American Academy of Physical Medicine and Rehabilitation which is the medical specialty society of physicians, and the Association of Academic Physiatrists or Physiatrists, depending on which part of the country you come from.

Due to your efforts, Chairman Harkin, this is probably the year of the disabled as evidenced by the unique passage of the Americans With Disabilities Act. However, despite the leadership of individual Members of Congress, such as yourself, we have lagged behind in our commitment of funds to address the total cost of disability in this country of $120 billion annually. In my testimony, Mr. Chairman, I am going to focus on a number of programs which we feel serve the disabled.

First of all, we would recommend full funding of the programs under the Rehabilitation Act that would include such things as the Rehabilitation Services Administration programs, the Federal/State rehabilitation program, the independent living programs, and others such as the research and training centers and the head injuries, spinal cord demonstration programs under the NIDRR, the National Institute of Disability, Rehabilitation, and Research.

When it passed the original legislation, creating the NIDRR, it was the intent of Congress that it would have an established $100 million program by 1980. We are now in 1990 and the proposed budget is about one-half of that amount. We clearly have not supported this program adequately and we would hope that we could see some of that this year.

Second, we would wish to support expanded research on disability at the National Institutes of Health. We believe NIH has a unique capacity to integrate the expanding knowledge in basic, physical and clinical research related to the improvement of disability and to provide rehabilitation.

We were pleased to note that after your committee report last year, calling for expanded research efforts last year at NIH, that the National Institute on Aging and the National Center for Nursing Research have, indeed, developed programs, particularly in the area of dealing with function in the frail elderly. And we would support what I believe is $28 million to add to that effort this year for research there.

In addition, Mr. Chairman, we urge the committee to provide funds for the startup of the National Institutes of Health National Center for Medical Rehabilitation Research authorized in Senate bill 1392. In November 1989, I served on an NIH panel on physical medicine and rehabilitation research, and that panel recommended creation of such a center, and all the panel members felt strongly that NIH needed to exercise leadership in the rehabilitation research field.

And finally, we urge funding of at least $10 million for the CDC disability prevention program authorized by Senate bill 2153, which you have sponsored. Among other things, that bill would provide funds for the development of State and local programs to educate the public, consumers, and professionals as to methods to prevent and reduce primary and secondary disabling conditions.

### PREPARED STATEMENT

In summary, the legislative programs that we support, we believe would collectively help to reduce disability, to prevent disability and to support medical and vocational research and technology to improve the lives of our disabled citizens. Thank you.

[The statement follows:]

# STATEMENT OF DOROTHY GORDON, JOHNS HOPKINS SCHOOL OF NURSING ON BEHALF OF THE AMERICAN CONGRESS OF REHABILITATION MEDICINE

My name is Dorothy Gordon. I hold a doctorate in the nursing sciences (D.ScN.) and I am on the faculty of the Johns Hopkins School of Nursing. I am also President of the American Congress of Rehabilitation Medicine, an interdisciplinary professional society representing some 3000 nurses, physical therapists, physicians, psychologists, occupational therapists, speech pathologists, social workers, and others who practice medical rehabilitation in a team process. I am also testifying on behalf of the American Academy of Physical Medicine and Rehabilitation, a medical specialty society of 3500 physicians and the Association of Academic Psychiatrists, a related academic medical organization.

Medical rehabilitation care, at least for inpatients, is an interdisciplinary team effort whose goal is the restoration of physical function and concomitant social and vocational function for the disabled person. Health care professionals in rehabilitation view the patient or client in terms of the whole person. We are very concerned with family, recreational matters, as well as return to work. We serve individuals of all ages from young children with spina bifida to 90-year-old stroke victims. The case mix in medical rehabilitation includes some of the most severe disabilities such as spinal cord injury, head injury, amputation, cerebral palsy, spina bifida, arthritis, multiple sclerosis, and muscular dystrophy. We have worked closely with and support the positions on appropriations of the Consortium of Citizens with Disabilities and the Rehabilitation Coalition.

My testimony focuses upon a number of related programs which serve the disabled. Due to your efforts, Chairman Harkin, this is the year of the disabled evidenced by the imminent passage of the Americans with Disabilities Act. About 15 percent of our population suffers from some form of disability and the total cost of disability to the nation is $120 billion. The cost of disability to the federal government from Social Security, SSI, Medicare and Medicaid payments alone is about $60 billion. However, despite the leadership of individual members of Congress, we have lagged behind in our commitment of funds to prevent primary and secondary disability, to restore function in the disabled and to provide the necessary medical, social and vocational research and technology development to reduce disability.

First, Mr. Chairman, we would recommend full funding of programs under the Rehabilitation Act including among RSA programs the federal/state vocational rehabilitation program, the independent living program, and the

$35 million program for training of professionals. For the NIDRR programs, we support $60.8 million for the National Institute of Disability and Rehabilitation Research general research authority, $20 million for the technology assistance program and $6 million for the spinal cord injury program. The NIDRR supports regional research and training centers, service demonstration projects and engineering centers, all of which are intended to improve the quality of rehabilitation service programs and reduce disability. We believe that the $6 million increase for the NIDRR general research authority should be used to expand funding for the 30 rehabilitation research and training centers which have not had increases for a number of years, to expand the spinal cord and head injury demonstration programs, and to fund more field initiated grants (FIGs). Only 25 new grants are planned for the FIG program in 1991 whereas the original intention was to fund 50 new projects per year.

Mr. Chairman, the original legislation creating what is now the NIDRR had authorization levels for 1978,, 1979, and 1980 of $50 million, $75 million and $100 million. The intention of Congress was to establish a $100 million program by 1980 which, with ordinary inflation growth should be about $200 million today. We have clearly not supported this program adequately although the addition of the technology assistance program has added substantial new funds to the NIDRR.

Second, we wish to support expanded research by the National Institutes of Health into the causes of disability, into techniques of medical rehabilitation care to reduce disabling conditions and the development of new and more effective devices to enable the disabled to function independently. NIH has a unique capacity to integrate our expanding knowledge in the basic, physical sciences with our clinical knowledge relative to improved rehabilitation and restorative medicine. Last year your Committee directed NIH to develop a comprehensive plan for medical rehabilitation research and submit it to the Committee by January 1990. Your report called for specific expanded efforts by the National Institute on Aging (NIA), the National Center for Nursing Research (NCNR), and the Child Health and Human Development Institute. We are pleased to report that the NIA and NCNR have developed programs particularly in the area dealing with the needs of independent function of the frail elderly. We have not seen evidence of expanded activity by other agencies of NIH however. We are also unaware of any plan to expand research in NIH for rehabilitation programs in 1990.

We strongly endorse the plan to expand research related to the frail elderly by $28 million in the NIA. Those funds and additional funds for the NCNR will permit an expanded clinical trial related to the frail elderly, expanded research on musculoskeletal disorders of gait and balance, geriatric rehabilitation research training and research related to incontinence. The focus on the frail elderly program is basically on medical rehabilitation to improve function of our aged disabled population.

In addition, Mr. Chairman, we urge the Committee to provide funds to start up the NIH National Center for Medical Rehabilitation Research authorized in S. 1392. This legislation passed the Senate in 1988 and has recently been reported by the Senate Labor & Human Resources Committee. The Center would be authorized to develop with other NIH agencies, a plan of research for all of NIH regarding medical rehabilitation and specifically to fund training, clinical trials, and individual research grants. The Center would focus on physical disabilities of the neurologic and musculoskeletal and related systems. In November 1989, NIH created a Panel on Physical Medicine and Rehabilitation Research. I served on that Panel of 18 experts advising NIH. The Panel recommended the creation of such a Center and funding of research by it. Panel members included scientists, health professionals, and consumer representation. It was chaired by Edward Brandt, M.D., who was President Reagan's Assistant Secretary for Health. All Panel members felt strongly that NIH needed to exercise major leadership in the rehabilitation field.

Mr. Chairman, NIH has enormous potential to assist our national effort to reduce disability and enable disabled individuals to function independently, but it has been very slow to take the necessary leadership except at the Aging Institute and Nursing Center. The National Center for Medical Rehabilitation Research can lead the NIH effort while supplementing the efforts of existing NIH agencies such as the NIA and NCNR. We urge the appropriation of $15 million for the Center to support a broad research training program, a general solicitation of research applications targeted upon improving medical rehabilitation diagnostic and therapeutic methods to deal with conditions such as head injury, stroke, arthritis, spinal injury, spina bifida, multiple sclerosis, and expanded research regarding prosthetic and orthotic devices and related technology.

Finally, Mr. Chairman, we urge funding of at least $10 million for the CDC disability prevention program authorized by S. 2153 which you have sponsored. That program builds on the $4.4 million existing program at CDC. S. 2153 would provide funds for the development of state and local programs to educate the public, consumers, and professionals as to methods to prevent or reduce primary and secondary disabling conditions. The program would also fund service demonstrations aimed at reducing secondary disabilities or complications which further disable already disabled people. The primary prevention program is aimed at injury prevention and congenital or birth defects. Both the pediatric and rehabilitation medical communities have been actively working with this program.

Disability is a very serious public health problem. We have numerous disabled people whose conditions go unnoticed and unaddressed. This CDC program should assist in providing greater access to medical health care and other services for the disabled.

Thank you, and I am available for any questions.

Senator **Harkin**. I hope we can get that through and get the money for the prevention program.

Dr. **Gordon**. That would be a major contribution.

Senator **Harkin**. We will do our best on that.

Dr. Gordon, thank you very much for being here and for your testimony. I have a list of your recommendations. Again, we will do our best, see what we can do to get up to it.

Dr. **Gordon**. Thank you for your support and for your ear.

Senator **Harkin**. I think you two advocates ought to meet each other here.

### STATEMENT OF JIM SWAIM, EXECUTIVE DIRECTOR, UNITED ACTION FOR YOUTH IN IOWA CITY

### ACCOMPANIED BY GREGORY L. EVANS, DEPUTY COUNSEL, NATIONAL COALITION FOR THE HOMELESS

Senator **Harkin**. Next, Jim Swaim, from Iowa City, the National Network of Runaway and Youth Services, and Greg Evans, deputy counsel, National Coalition for the Homeless.

I appreciate your being here, Jim. We have talked before, in my office; I met your family. And I appreciate seeing you here today.

Mr. **Swaim**. Thank you for the opportunity, Senator. What I want you to remember from Iowa Day, as you might call this morning, is that we have an urgent need for Federal leadership to help runaway and homeless youth.

Specifically, we are desperate for improved funds for youth services. We are seeking $50 million in Runaway and Homeless Youth Act funds and an additional $25 million for the transitional living program, $20 million for the drug abuse prevention program, and $20 million for the gang prevention program. We also need urgent research in HIV-AIDS prevention and treatment.

You know Senator, I am lucky to be doing my work in Iowa. Our shelters in the Midwest only have to turn away every other child who is seeking help. Some programs have to turn away three young people for every one that they admit or that they have room for. In the Midwest, Missouri, Iowa, Nebraska, and Kansas have about 350 beds that are supported by basic center grants. That is nowhere near enough beds to provide services to runaway and homeless youth.

Before Christmas, I did a peer review of the Wichita Children's Home, which gets less than $20,000 annually in basic center support and sheltered over 1,200 kids. We need your help. It is desperate. You have offered some great comparisons this morning. I would like to offer another one.

We do more things for sheep in this country and for those who raise sheep than we do for runaway and homeless youth. The Federal Government needs to help or we need the help of the Federal Government to shepherd our runaway and homeless youth so they are not permanently loss to our Nation.

### PREPARED STATEMENT

In Iowa, you recall in my testimony, a woman named Cora Busey Hillis in 1917 almost got funded the Child Research Center. That year, sheep farmers descended on the Iowa Legislature and at the last moment of the legislative session, were able to convince them to build a new sheep barn in place of the child research station, which now has become the University of Iowa Child Development Clinic. So some things do not change.

[The statement follows:]

# STATEMENT OF JIM SWAIM, EXECUTIVE DIRECTOR, UNITED ACTION FOR YOUTH IN IOWA CITY

Mr. Chairman and Members, thank you for the opportunity to address you. My name is Jim Swaim. I am Executive Director of United Action for Youth in Iowa City, Ia., a multi-service, community-based agency for youth and their families. My agency is a member of the National Network of Runaway and Youth Services (NNRYS), on whose behalf I am testifying today. The National Network brings together hundreds of community youth service providers to share ideas and improve our individual abilities to serve youth and families.

I am here to talk about the urgent needs of runaway, homeless, and other high-risk youth and the desperation they face in trying to get help for themselves and their families. An estimated 1.3 million American teenagers run away each year or become homeless. Runaway and homeless youth represent every segment of American life: they are of every color, ethnic group, sexual orientation, and religion; they are rural, urban, and suburban; and they came from affluent, poor, and working-class neighborhoods before they ran away or became homeless. Characteristically, they stay within 10 miles of their families' homes.

In 1975, the federal government took its first major step to address the needs of runaway and homeless youth by making funds available under the Runaway and Homeless Youth Act (RHYA) for community-based programs known as Basic Centers. Every Basic Center in every community funded since then has documented what was recognized when RHYA was drafted: runaway and homeless youth are not living on their own to realize dreams of personal autonomy and adventure; they're often leaving desperate situations.

They're fleeing parental neglect, sexual and/or physical abuse, or other chaotic situations like family violence or parental alcoholism or substance abuse. They are sometimes forced from their homes by parents who are unable to cope with their own marital, economic, or emotional problems and find caring for a teenager beyond their capabilities. In addition, too many have been failed by the child welfare system and come to view the streets as preferable to endless shuffling between foster families and group homes.

These young people have few skills or life experiences with which to earn a living. Many must rely on "survival sex" just to ensure a place to stay each night or for food, rides, and clothes. They appear invisible to many, because they are disconnected from community life. They lack access to schools, health care, families, counseling services, and other community support systems. Many of them are in need of mental health care due to substance abuse or depression. Their behavior and life circumstances put them at risk for many debilitating problems including drug abuse, early pregnancy, and HIV infection/AIDS. (Please refer to attached supporting reference data.)

Basic Centers proved in the 1980s that, like Headstart, they are extremely cost-effective. They provide a comprehensive range of services to help communities respond to the increasingly complex problems of raising homeless children.

This year in Iowa five Basic Centers will provide services and shelter to a few thousand children and families using about $300,000 in Federal Basic Center grants. Despite their success, three of the Basic Centers in eastern Iowa will compete this year for less funds. Our program in Iowa City will be competing with needed programs in Cedar Rapids and the Quad Cities (Davenport) for funds equal only to what now operates the Iowa City and Cedar Rapids Basic Centers.

The National Network is aware of the seriousness of the budget deficit facing the 101st Congress. However, we also know from programs across the country that young people are struggling to find food and shelter while falling prey to a number of health, drug abuse, and other problems. Critical services such as crisis intervention, housing, prevention programs, and transitional living will not only provide youth the opportunities they deserve, but will make a long-term economic investment in our future.

**The Runaway and Homeless Youth Act (RHYA)** programs have continued to expand services to help meet the increasing needs of vulnerable youth and their families. However, federal support for existing programs has not kept pace with the need, forcing agencies to turn young people away from services. **We urge you to support a $50 million appropriation for shelter, hotline, and other services defined in RHYA.**

**The Transitional Living Grant Program for Homeless Youth** is designed to provide residential and support services to homeless youth "to promote a transition to self-sufficient living and to prevent long-term dependency on social services." It is a needed extension of the runaway programs, serving those youth who cannot be reunited with their families and have no safe place to live. **We urge you to support a $25 million appropriation for this program.**

**The Drug Abuse Prevention Program for Runaway and Homeless Youth** and the **Youth Gang Prevention Program** provide help for at-risk young people, avoiding wasted years and costly periods of incarceration in jails or hospitals. **We urge you to support a $20 million appropriation for each of these two programs.**

Finally, we are very concerned about the numbers of young people who risk contracting the HIV virus. Public health experts predict that adolescents will form the next wave of this epidemic. **We urge you to support adequate funding levels for HIV/AIDS prevention programs, research, and care.**

I must confess to feeling great pressure as I prepared this brief testimony. I took some courage, however, in recalling some of the experiences of one of Iowa's pioneer youth advocates and one of its great leaders, Cora Busey Hillis.

Cora was a leader in the National Mothers' Congress at the turn of the century. Like the National Network, the Mothers'

Congress was a national grassroots movement to address the needs of children, including orphans and runaways.

While Cora was very successful in work with the Mothers' Congress, she struggled for years with the Iowa Legislature. Year after year, Cora would plead with legislators to begin to look at the developmental needs of children. In 1917, her years of hard work were about to pay off as the legislature gave tentative approval to fund its first child research program.

In the waning hours of the session, as will happen during appropriations, a competing proposal for funds emerged: in this case, a proposal for a new sheep barn for the Iowa State Fairgrounds. At the last minute, as sheep farmers converged on the statehouse, the new barn was approved at the expense of Cora's child research station. She described that as one of the most disappointing moments of her life.

The following year, when 209 of 250 Iowa boys were unable to pass the physical entrance exams to assist in the war effort, Cora returned to the legislature and shamed them into the immediate approval of what is today the University of Iowa Child Development Center.

"We should care as much for our children as we do for our sheep," she argued, pointing out that Iowa was now less able to help America defend democracy.

For the record, under the National Wool Act of 1954 as extended through 1990 by the Food Security Act of 1985, USDA payments to farmers to help raise sheep over the last three years came to over $232 million (ASCS Commodity Fact Sheet, April 1989). In that same period, federal support to Basic Centers was less than $70 million.

I'm very grateful for your consideration of my testimony. I only wish Cora Hillis could join me to speak of the urgent needs of our most desperate children.

## RISK FACTORS KNOWN TO THE MEMBERS OF THE NATIONAL NETWORK

### Consequences of Street Life

o HIV infection/AIDS. Some programs for runaway and homeless youth in high-incidence areas report that 7-15% of their clients who have been tested for HIV are infected. Homeless youth, infected or not, often lack HIV prevention information, the negotiation skills necessary to practice safer behavior, and access to condoms or bleach for needles. Too often, because of their profound isolation, homeless youth lack the will to save their lives through less risky behavior.

o Emotional Problems. Suicidal ideation and attempts run as high as 60% among homeless and runaway youth. Reported rates of clinical depression among homeless youth range from 29 to 84% (Shaffer & Caton 1984; Yates et al. 1988).

o Early Pregnancy. In a study that focused on health services to homeless people in 19 cities, girls aged 16-19 had the highest pregnancy rate of any other age group. Thirty-one percent of the 16-19 year-olds receiving health services were pregnant, as compared to 9% of the control group used (Wright 1989).

o Health problems. Street youth are nearly twice as likely to have chronic physical ailments as non-homeless youth (Wright 1989).

o Drug and alcohol abuse and dependency. Reported rates of substance abuse among homeless adolescents range between 70-85% (Shaffer & Caton 1984, Yates et al. 1988, Rotheram-Borus, Koopman & Bradley 1989).

Preventing or treating these problems is very difficult given the lack of stability in these young people's lives. Just securing shelter on a day-to-day basis and remaining relatively safe from assault is consuming. There is also an increased chance that these youth will become involved in criminal activities as a means to fit in, express their rage, and secure basic needs.

### Barriers to staying off the streets

The federally-funded system of runaway and homeless youth centers is designed to keep young people off the streets. Stressing family reunification, the centers report that over three-fourths of the youth served return to their families or to alternative placements. However, many young people are not being served.

Often programs are full and must turn away teens seeking residence in order to stay in compliance with state and local licensing. Program expansion is difficult given that federally-funded youth shelters receive annual grants ranging from only $22,000 to $150,000.

Youth who cannot be served have few options. According to Office of Juvenile Justice and Delinquency Prevention data, as many as 3,234 status offenders (e.g., runaways) were locked in detention facilities in 1988. Many would that this experience hardens young people, increases their alienation, and makes reconnecting with community life more difficult. Safe alternatives to lock-up are needed.

Adult homeless shelters are also inappropriate for these young people. Shelters for the adult population often refuse to serve youth younger than 18 years, and shelter life presents many dangers for teens -- e.g., sexual and physical assaults. In addition, there are no services at these shelters to motivate youth to return to their families or schools and to make decisions that will keep them safer and healthy.

The federally funded centers are allowed to provide emergency shelter and crisis intervention services for up to 15 days. However, some youth need longer periods of assistance and may be forced back on the streets as most communities do not have transitional living services. Of the approximately 68,000 youth served at runaway and homeless youth centers in FY 89, approximately 14% had no planned destination or returned to the streets after their stay (OHDS Family and Youth Services Bureau). Not having a place to go or any hope of stable living situations keeps many youth from seeking help from centers and other social services.

### STATEMENT OF GREGORY L. EVANS

Mr. EVANS. Mr. Chairman, my name is Gregory Evans, I am deputy counsel for the National Coalition for the Homeless.

Briefly, we would just like to validate Mr. Swaim's comments. During the week on December 6, the national coalition conducted a telephone survey of federally assisted shelters throughout the country. They uniformly report that the needs of homeless and runaway youth far exceed the available supply.

The other point we would like to briefly state, Mr. Chairman, is that in this country homeless and runaway youth are being locked up in adult and juvenile correctional facilities in some places because there is nothing else available for them. In Kentucky, for example, over 1,300 runaway and homeless youth were locked up in adult and juvenile correctional facilities simply because there was nothing else available for them.

### PREPARED STATEMENT

Together with the National Network for Runaway Youth, we are also requesting an increase in appropriation, which is very much needed under the Runaway and Homeless Youth Act. On behalf of the National Coalition for the Homeless and, most importantly on behalf of the homeless and runaway youth who are today on our streets, we thank you for your support and for your consideration and your commitment to the welfare of children, and most specifically to the welfare of homeless and runaway youth.

[The statement follows:]

## STATEMENT OF GREGORY L. EVANS, DEPUTY COUNSEL, NATIONAL COALITION FOR THE HOMELESS, WASHINGTON, DC

Today, the people of the United States are more aware of the pervasive homelessness crisis in our country. Yet, when homelessness is debated and solutions are proposed, homeless and runaway youth are regularly overlooked as a segment of the homeless population also needing immediate assistance.

Homeless and runaway youth are a distinct and fast growing segment of the homeless in our country. The National Coalition for the Homeless estimates that at least one million American children were homeless and unaccompanied by a parent or guardian at some time during 1989.

Contrary to popular thought, most homeless and runaway youth do not leave home seeking to satisfy some sense of adventure. In fact, most do not have safe homes to which they can return after a brief stay on the streets.

Today, most homeless and runaway children are fleeing destructive home environments. A December 1989 General Accounting Office report on homeless and runaway youth documented that 82 percent of children assisted at federally funded shelters were subjected to parental neglect, physical or sexual abuse, drug or alcohol abuse or domestic violence before leaving home.

During the past decade, increasing numbers of children were "thrown away" by parents, who, because of drug, emotional or other problems, could not continue to care for them. According to a recent report of the House Select Committee on Children, Youth and Families, approximately 500,000 American children were actually forced out of their homes in 1989 because of alcohol or drug abuse, homelessness, family breakup, poverty and child abuse or neglect. In short, the choice for many children is either to stay and suffer - and perhaps perish - or to flee.

Homelessness among families is also causing an increase in homeless unaccompanied youth. The number of homeless American families is growing almost exponentially. Recent studies by the

Department of Housing and Urban Development indicate that, on any given night, the proportion of shelter-using homeless families increased from 21 percent in 1984 to 40 percent in 1988.

A seldom discussed result of family homelessness is that children in homeless families are regularly removed from their families and placed into foster care. Increasingly, parents unable to provide a home are considered unfit to care for their children.

Notwithstanding the devastating impact such placements have on family integrity and well being, such placements are usually unsuccessful, especially among older children, since many youth would rather attempt to make it on their own than to have strangers care for them. As a result, many children of homeless families take to the street with no where to go and, most often, with inadequate services available to assist them.

Failing foster care systems are also contributing to homelessness among youth. The nexus between failing foster care services in our country and the increasing incidence of homelessness among youth is very close. Far too often, children are discharged from foster care with neither the resources nor the ability to manage on their own. As a consequence, these children usually become homeless.

Other youth are pushed out of foster care too early because the foster care system is overburdened and unable to offer stable placements. The number of children placed in foster care in America is rising dramatically. It is estimated that the number of children in foster care rose 23% between 1985 and 1988 (340,000 children in foster care in 1988 as compared to 276,000 in 1985). With the number of children such care increasing, the number of available placements are is reported to be remaining constant.

Although Congress sought to address the inadequacies of the foster care systems throughout the country during the 96th Congress - through passage of permanency planning legislation

(P.L. 96-272) - children continue to be bounced from placement to placement because beds are available only for brief periods and permanent placements are not sufficiently pursued. In short, many foster care children become the subtle throwaways of our child welfare service system and wind up on the street.

Tragically, children thrown away and into the street are easily victimized and usually suffer psychological and physical harm. Homeless youth are preyed upon by pimps, drug dealers and molesters. They are at extremely high risk of contracting AIDS. They are harmed by older people taking advantage of their vulnerable condition. Although we are aware this harm to our nation's youth is occurring, services which may actually prevent such injury are veritably insufficient.

During the week of December 11, 1989, the National Coalition for the Homeless surveyed federally funded programs assisting homeless and runaway youth in the United States. The agencies surveyed uniformly report that their shelter, health, psychological and other essential services are not sufficient to met the needs of homeless youth in their communities.

The current lack of emergency shelter assistance for homeless youth is exacerbated by administrative and financial trouble within the nation's largest provider of services to homeless and runaway youth, Covenant House. This single organization at one time devoted three times as much in private resources for homeless and runaway youth as the federal government.

Unfortunately, the difficulties within this organization will likely result in a significant reduction in services to homeless youth. The troubles currently endured by the nation's largest provider of services to homeless youth necessitate an immediate increased appropriation for the Runaway and Homeless Youth Act in order to prevent further suffering and harm.

There is simply not enough emergency shelter assistance for homeless and runaway youth. In many cities, they are refused entrance to overcrowded shelters. In some places, homeless youth are actually locked up in adult jails and juvenile detention facilities because there are no emergency shelter services to assist them. In Kentucky, for example, during 1989 1,311 homeless or runaway children were locked up in adult and juvenile detention facilities for this reason.

In addition to the need for additional shelter assistance, other vital needs of homeless youth are not being met. Mental health problems are acute. The incidence of psychological problems is increased by the disruption and disorientation of homelessness. In fact, most studies report that over 80 percent of homeless youth exhibit some symptoms of psychiatric disorder. Yet homeless children cannot expect to receive adequate treatment and counseling because insufficient resources are allocated for the purpose of providing mental health care for this population.

Homeless youth have critical physical health needs not being addressed. Seven to ten percent of the homeless youth screened in a recent New York City survey tested positive for the AIDS virus, a rate which increased to 20 percent in a group of adults who were formerly homeless youth. The high rate of seropositivity is linked primarily to frequent sexual activity, often in exchange for money for food, shelter or drugs. Hepatitis, malnutrition, and other disease and injuries are pervasive among homeless youth.

Since its inception in 1974, the Runaway and Homeless Youth Act essentially saved the lives of hundreds of thousands of homeless young Americans by providing shelter, counseling and other vital services. The Runaway and Homeless Youth Program is invariably referred to as a laudable, effective federal program.

Even though the programs administered under the Runaway and Homeless Youth Act provide services in the manner contemplated by Congress, as stated, existing programs are not sufficient to meet the urgent needs of homeless and runaway youth. Accordingly, an increase in appropriation under the Runaway and Homeless Youth Act is needed.

Health services to homeless youth must also be improved and expanded. Currently, an agreement facilitated by the Department of Health and Human Services between homeless youth shelters receiving federal assistance and the Public Health Services allows homeless children, unaccompanied by a parent, to avail themselves of health services offered to the adult homeless population at shelters and health centers.

This method of providing health care to homeless youth is inappropriate. It risks greater harm, abuse and injury to vulnerable youth by requiring them to enter adult homeless shelters to get medical care. Locating medical care for runaway and homeless youth in usually daunting adult homeless shelters acts to deter youth from obtaining the medical care they need.

Federal funding for permanency planning services must be also be increased. Despite dramatic increases in the number of children in foster care, federal funding has not kept pace. Funding for child welfare services providing important prevention and reunification support to families is stagnant and remains below the authorized spending for 1980. With additional abuse prevention and family reunification support, presumably, fewer children will be forced to flee destructive homes.

Despite the demonstrated need of homeless youth for mental health services, the principal federal support for mental health services - the Alcohol, Drug Abuse and Mental Health Block Grant - provided $17 million less in fiscal year 1989 than in 1981. There is no separate, adequate funding for children's mental health services.

Even though homelessness among families has increased to include more than one million Americans, the Department of Housing and Urban Development completed 1989 with a contemptible record of ineffective assistance for the over one million homeless families in America. There can be no denying that a connection between homelessness among youth and a lack of available, suitable permanent homes definitely exists. An increase in low income housing assistance would no doubt serve to partially abate rising foster care placements and homelessness among youth.

CONCLUSION

Without additional help, the outlook for homeless youth in the 1990's is bleak. Programs to assist homeless and runaway youth are truly a good investment for the children themselves as well as for the future of our country. If adequately assisted today, it is less likely that these children will rely upon already overburdened social service administrations in the future.

A bolder, more substantial federal response is needed. Emergency shelter and transitional living programs for homeless and runaway youth are abjectly insufficient. They must be expanded. Finally, if we are to stem the increasing number of homeless youth in America, increased supportive services to families is needed.

Your leadership, Senator Harkin, and the leadership of the entire Subcommittee is desperately needed to facilitate a redirection of resources to relieve the suffering of homeless and runaway youth and to adequately fund programs which can successfully prevent deterioration of the American family.

Senator HARKIN. Thank you.

Let us see. What have we got in here in funding for this; $28.785 million last year, and the request is level funding this year, and you are recommending $50 million level for that. What would that mean in terms of Iowa?

Mr. SWAIM. In the coming year our basic center and two other basic centers are up for competition, and there is less funding available in the coming year than what currently funds our three basic centers. So, it will mean not defunding one of our basic centers, or at least would hopefully mean that, and that is true in many States around the country.

Again, $20,000 for Wichita, that is not even one staff person, Senator. So, it would mean adequate staffing, needed professional help and care for literally hundreds of thousands of children and homeless youth.

Senator HARKIN. We will try our best. I was reading that $230 million for sheep in the last 3 years. That is pretty interesting.

Mr. SWAIM. Johnson County, which is not exactly a large sheep producer, gets more money in Johnson County for sheep than we get in our basic center grant. But we are proud of what we do for both.

Senator HARKIN. It is a good comparison. Thank you very much.

## STATEMENT OF MARY BOURDETTE, DIRECTOR, OFFICE OF GOVERNMENT AFFAIRS, CHILDREN'S DEFENSE FUND

Senator HARKIN. Next is Mary Bourdette, Children's Defense Fund.

Ms. BOURDETTE. Thank you. On behalf of Mary Nettleman and all of us at the Children's Defense Fund, Senator. I want to thank you not only for the opportunity to testify here today, but for your consistents perhaps I ought to say persistent leadership on behalf of children.

We are here today making a plea that we and many others and you have been making for so long that it is time for our Nation to make a significant national investment in children, particularly in our youngest and poorest and most disadvantaged children.

If we have any chance at all to meet the many challenges that are ahead and to maintain in any way the political and economic leadership that we have had in the past. And finally, as you know, after many years there seems to be a developing, rapidly developing consensus around a certain set of goals for our children in our Nation, but unfortunately among those same political leaders there seems to be less enthusiasm for the investments that are absolutely essential if we are going to meet those goals and have our children ready to enter school and excel and become the productive and prepared work force that we need and not the homeless children and the dropout children that none of us want and that is costing our country their lives and many dollars as well. So, I want to thank you, Senator Harkin, for the leadership that you have already provided and the opportunities that are immediately available to us for this year.

We think that three investments are absolutely essential this year, three key investments along with many others. And the first is child care. Here we are again. We do not need to tell you or families that we have a child care crisis in this country. We do not need to tell you or other parents that very few parents feel comfortable with the choices that are available to them because our governments have provided virtually no assurances that the child care programs are safe, even minimally safe and have provided few dollars for those parents who cannot afford child care costs that you know are $3,500 a year or more.

The Senate did produce a very fine child care bill. We are hoping and praying that the House today will complete action on a similar child care bill. We are about to have a vote.

Senator HARKIN. It sounds like they are going to go in a little bit different direction.

Ms. BOURDETTE. No; I believe in the end the bills will be very similar. They both will provide the minimum $1.75 billion to help parents pay for care to be allocated to the States. Also, to improve the quality of care. They will maintain the same quality and safety assurances that are in the Senate bill.

Senator **Harkin**. Well, that is good.

Ms. **Bourdette**. They are in the bill as well as the same language with respect to church state that is in the Senate bill.

Senator **Harkin**. They used the same language?

Ms. **Bourdette**. The same language as in the Senate bill, and they also have a package of tax credits similar to the Senate. Part of the bill is funded through the title XX program. But nevertheless, the overall amount is still the $1.75 billion. So we are hopeful that this bill will pass and that the opposition put forward by Representative Stenholm which seeks to delete not only the quality assurance but the very right of parents to visit child care programs are a very important part of our Senate bill and our House bill will not be eliminated.

Senator **Harkin**. Will he offer that as a substitute?

Ms. **Bourdette**. Yes; that will be offered very soon on the floor. But we are hopeful that we will pass a bill that has this $1.75 billion and that—it was tragic that the funds that you provided last year were lost.

Senator **Harkin**. I am getting the feeling that when you talk about safety of child care and ensuring a safe environment for child care people are saying well, leave it to the parents. Just give the voucher to the parent. The parent can decide whether or not it is safe or not. They do not have to be treated like children. Parents can decide. How do you respond?

Ms. **Bourdette**. In fact, is the parents more than anyone else who are asking for assurances that the child care is safe and of decent quality. You do not need to go very far. You can walk out on the street and ask any parent in day care do they feel comfortable with the care, do they know enough about the care that is out there, and virtually every one of them will say no.

We want you as a Senator and State legislators to give us some assurances. The polling confirms what we hear from every parent. It is overwhelming support around the country, in every region, among every category of voters in support of health and safety provision in child care.

And despite the opposition that you hear, it is the parents who are most vocal and most supportive of helping that, and that is why, for example, the Senate bill and the House bill that we are hoping will pass will provide parents a simple right to visit their program whenever they want and yet those who oppose standards are saying no, we want to give parents that right. We want to eliminate those kinds of provisions from the bill. It is very hard to understand that.

And so most important has been getting out the word of what is and is not in these pieces of legislation because the parents are the most supportive group of quality improvement provisions along with people who provide day care.

Most of them are also well aware of those assurances, and they want to give them, but unfortunately they have not had much support in that. So, they are hopeful we will have legislation and we will be working with the Budget Committee to make sure that you have the budget authority that will allow the $1.75 billion appropriation for child care this year.

Senator **Harkin**. I put in some last year. At least we can get it started anyway.

Ms. **Bourdette**. And almost 500,000 children were denied day care because the House did not finish its action last year.

Senator **Harkin**. I am sorry, I did not mean to get off on that.

Ms. **Bourdette**. The other critical investment which we feel is absolutely essential this year is to significantly expand the Head Start program, again something you have been very involved in.

We have a plan in the Senate and one introduced in the House that would put us on a path toward full participation in Head Start by 1994. That is essential if we are going to prepare children for school. That is a $1.4 billion increase in the program this year. Obviously that is significant, but not when we compare it to the other priorities which, unfortunately, have taken precedence in the Congress these last few years. And again, Head Start people all over the country and many of us here in Washington will be working to make sure that the budget provides you the kind of authority you need to do that.

Senator **Harkin**. I hope so. That is what we need.

The first cut from the budget, as you know. Mary, can we use that money? I mean, if we were able to get that money, can it be utilized in a cost-effective manner in the next year? Are the people in place? Are the structures in place to do that?

Ms. **Bourdette**. We do believe we will be able to obligate the funds in the first year of that kind of increase, whether all of them will go out the door the first year.

Senator **Harkin**. That will not happen.

Ms. **Bourdette**. Certainly the programs are there.

Senator **Harkin**. I do not know what the obligation rate is on that.

Ms. **Bourdette**. It would be lower with these kinds of dollars, but some of these dollars have to be provided to improve the quality of Head Start.

Unfortunately, as with every other program, Head Start has been skimped on for the last few years. We need to put some dollars into buses to make sure kids can get to the Head Start program. We need to make sure that all the comprehensive services that have made Head Start successful are there. So, some of those funds are going to be to improve existing programs while adding a number of children.

Senator **Harkin**. The last is immunization.

Ms. **Bourdette**. There are many other needs, but we think we have an opportunity to provide perhaps $80 million of additional funds for the child immunization this year. I am not sure in Iowa, but in many of our core cities in the country we have an incredible outbreak of measles, mumps, and whooping cough and the CDC, I am sure, has testified about the need for additional funds to meet that new outbreak of preventable diseases.

Senator **Harkin**. I do not see it in your testimony. How many kids in America now under 10 or whatever have not been immunized?

Ms. **Bourdette**. I do not have that with me, but it is a significant portion of young children in central cities. Perhaps as much as one-half in the central cities are not immunized, young children, as of one, two, and three. By the time they get to school, they are often immunized, but that is often 200. So we have a particular need among the young children in our central cities.

You know there are many other children's needs, and you have heard about them today and at other times. And, again, we will be working with you, with the Budget Committee to make sure one of these years that we place children at the top of the national agenda and we put our money where our mouth is with respect to children.

Senator **Harkin**. Let me compliment the Children's Defense Fund for being such an outstanding advocate, especially here on the Hill and for always being there for the information we need and the support and the encouragement and the prodding, the organizing efforts to run the country.

The Children's Defense Fund is one of the best.

### PREPARED STATEMENT

Ms. **Bourdette**. Thank you very much, and thank you for always being there as well.

I know Marion appreciates those comments.

[The statement follows:]

## STATEMENT OF MARY BOURDETTE, DIRECTOR OFFICE OF GOVERNMENT AFFAIRS, CHILDREN'S DEFENSE FUND

The Children's Defense Fund wants to thank Chairman Harkin and the Subcommittee for allowing us to testify today.

For today's children, educational achievement is the key to adult opportunity. Children who learn to read, write, and compute effectively and who master the habits of mind that foster lifelong learning can look forward to challenging, well-paid work and to leadership roles in their communities. Children who do not master those skills and habits face a future of dead-end jobs, low wages, and marginal effectiveness in our increasingly complex society.

More than ever, the American public along with leaders from the business, academic and political communities are realizing that children must have their basic needs for good child care and preschool education, health care, nutrition and shelter met if they are to be prepared to achieve in school. Children who are warehoused rather than given the benefits of good child care and preschool programs, will enter school without the cognitive, language and social skills all children need and deserve. A child who is sick or hungry cannot possibly learn or excel. Neither can one who falls asleep in class because she was awake half the night before in a homeless shelter.

This Subcommittee has long understood these connections. CDF sincerely appreciates this Subcommittee for its long standing commitment to programs -- such as quality child care, Head Start, Chapter 1, and childhood immunizations -- that have been proven to help children thrive, develop and achieve and to support and strengthen families.

As America strives to meet the newly-formed national education goals put forth by the President and the nation's governors, it is especially critical that needs of children and families receive top priority throughout this year's budget and appropriations processes.

We urge you to continue and expand upon your previous efforts as you mark up the Labor, Health and Human Services and Education Appropriations bill for fiscal year 1991.

**Quality Child Care.** We strongly urge this Subcommittee to appropriate $1.75 billion in new funds for the soon-to-be completed child care initiative.

Child care is a major crisis for America's families as parents in every part of the country find it difficult, if not impossible, to find or afford safe and decent care for their children while they struggle to work and support their families.

Last year, Chairman Harkin and the Subcommittee played an instrumental role in responding to the child care plight of America's families. After the Senate passed S. 5, the Act for Better Child Care, last June, your commitment to fund this critical initiative for America's children and families was honored with a $1.2 billion appropriation for FY 1990. Because final child care legislation was not completed last year, families did not receive these desperately needed funds. As the child care crisis worsens and final action on comprehensive legislation nears, we urge your to appropriate $1.75 billion for child care in the FY 1991 Labor, Health and Human Services and Education appropriation bill.

**Head Start.** We also recommend that you appropriate $2.786 billion in FY 1991 for Head Start, or $1.4 billion over FY 1990 levels.

Business, academic, and political leaders all agree: Head Start is a cost-effective, early childhood development program that is successful in insuring that low income children are ready to enter school. Head Start responds to all aspects of a child's development and growth. Its four components -- social services, health, education and parent involvement -- help low income children reach their full potential while also addressing family needs that often pose obstacles to a child's full and healthy development.

Yet on this 25th anniversary of Head Start, less than 20 percent of all eligible children have Head Start services available to them. A plan already has been proposed in the Senate (S. 2229) to reauthorize the Head Start program and put it on the path to full participation by 1994 while strengthening the program's hallmark quality -- starting with an increase of $1.4 billion for FY 1991.

Consistent with this plan, we urge this Subcommittee to add $1.4 billion to the program this year.

**Childhood Immunizations.** We recommend an appropriation of $236 million for the Immunization program for FY 1991, an increase of $80 million over current spending. This funding is critical to halt the disturbing increase in outbreaks of preventable childhood diseases such as mumps, measles, and whooping cough (pertussis).

Immunizing children against preventable disease is the most effective and cost-effective way to avoid unnecessary illness and disabilities saving more than $10 for every dollar invested. We urge you to invest an additional $80 million in immunizations this year.

Children, of course, have many and varied needs, and we hope you will support additional funds for other programs vital to ensure the health of children, protect them from abuse and neglect, and prepare them for a productive future. The Children's Defense Fund also recommends funding increases for other, pressing needs of children and families in FY 1991.

**Child Health.** Since 1970, the **National Health Service Corps** has sent more than 13,000 physicians, nurses, dentists and other health professionals to work at health centers and in other underserved communities -- 70 percent of them serve in rural areas where the closest hospital or physician may be many miles away. We recommend a total appropriation of $130 million (a $79 million increase) for FY 1991 for the field operations and the scholarship and repayment programs.

Across the nation, thousands of local health departments and other programs receiving funding through the **Title V Maternal and Child Health Services Block Grant** have provided both basic and specialized health care to millions of low income children and children with special health needs. We recommend an appropriation of $686 million (a $133 million increase) for FY 1991.

For 25 years, **Community and Migrant Health Centers** have provided access to primary and preventive care and contributed to reductions of up to 40 percent in infant mortality rates in their communities. CDF urges you to add $85 million for these centers in FY 1991.

**Education.** In order to begin national action to meet the new educational goals, especially in light of the entry into school of large numbers of children born to substance abusing mothers, we urge you to place priority on early intervention programs for infants, toddlers and young children with physical, developmental, and mental disabilities.

We urge you to triple the current funding appropriation over the next four years for the **Education for All Handicapped Children Act (P.L. 94-142)**, and add up to $1 billion this year to the **Chapter 1 Compensatory Education Program** to meet the goal of serving all eligible children and strengthening program improvements.

In addition, CDF supports full funding ($25 million) for the President's proposed **principal training initiative** to help principals improve the performance of their schools.

**Support for Vulnerable Children and Families.** Due in part to growing poverty among children and young families, increasing numbers of homeless families, an inadequate health care system, and the epidemic of crack cocaine, vulnerable children and families and the child-serving systems charged with caring for their needs are in crisis. Increases in reports of child abuse and neglect when coupled with dramatic increases in the numbers of children in out-of-home care and severe staff shortages jeopardize the well-being of thousands of children.

A package of new initiatives designed to better serve children in the mental health, child welfare and juvenile justice systems is currently being developed by an ad hoc coalition of organizations that have advocated for years on behalf of children, adolescents and their families. Hopefully, this package will be introduced later this spring.

But in order to begin to address the crisis in child welfare now, we recommend funding the **Title IV-B Child Welfare Services Program, the Child Abuse Prevention and Treatment Program,** and **the Runaway and Homeless Youth Act** at their authorized levels of $325 million, $48 million, and $50 million respectively as well as fully funding the **McKinney Act for the Homeless.**

CDF also urges you to provide $40 million for the **Emergency Child Protective Services Grants** approved by Congress last year as part of the Drug Free Schools Act, and $60 million for the **Title IV-E Independent Living Program.**

**Job Training Programs.** Job training programs are essential to building the capacity of young workers to support themselves and their families.

Consistent with the President's request, CDF recommends an appropriation of $1.719 billion in FY 1991 (an increase of $253 million) for the proposed amendment to **Job Training Partnership Act** now pending in Congress to focus on job training for disadvantaged youth. We also support the President's request of an additional $50 million for a **new youth initiative** to focus on inner-cities and poor rural areas.

With a FY 1991 appropriation of $950 million (a $150 million increase), the **Jobs Corps** could reach an additional 4,000 highly disadvantaged young people with the supports that have been so effective in increasing their rates of school completion, employment and earnings.

## STATEMENT OF DAVID RHODES, CHAIRMAN, NATIONAL ASSEMBLY FOR VISUAL ARTS EDUCATION

Senator HARKIN. David Rhodes, chairman, National Assembly for Visual Arts Education.

I do not have written testimony for you.

Mr. RHODES. I will give it to you after I am through.

Thank you for this opportunity. I, unfortunately, am not from Iowa although judging by how things have gone today, I think that is my misfortune.

I also do not envy your position having sat through the testimony thus far. These must be difficult choices for you.

I am David Rhodes, and I come to speak for the future of art and design education in America. I am current chairman of the National Assembly for Visual Arts Education, an arts advocacy consortium formed by several like-minded college presidents. I am also president of the School of Visual Arts in New York City, our Nation's largest college of art and design.

I am here to call your attention to the absence of art programs in the proposed Department of Education budget for fiscal year 1991. I personally represent more than 7,000 undergraduate and graduate students and all of their concerns, but due to time constraints I will limit myself to two essential areas that this budget neglects: Federal basic support for arts programs grade K through 12, and graduate study in art, and particular design disciplines.

Unfortunately the proposed Federal education budget is far more limited than even these modest remarks. In fact, while the budget pays some lip service to the arts, actual art and design are not mentioned in letter or in spirit in the 87 pages of the document. This by now, unfortunately, visionless way comprises nothing less than a continuing tragedy for America's schoolchildren, a denial of fundamental educational rights and a dangerous oversight in America's planning for the future.

As usual, the budget does specify certain curricular areas with some precision, mathematics, but the visual arts are completely ignored. For example, the language described in the $213 million magnet schools programs fails to include the visual arts in its description, sources of some of the oldest and most successful magnet programs nationally.

Please understand that art has little hope of generating significant local support and funding unless the Department of Education sets a national example. There is a little argument concerning the impact and importance of art in elementary and secondary education.

Around the Nation art magnet schools are achieving remarkable results across the curriculum and arts based activities have proven especially effective in reaching children at risk.

Critical support from the Department of Education is required now to help put new art teachers in classrooms and to develop and bring new initiatives to fruition.

Concerning support for graduate and advanced professional study I would remind you that design is a critical component of America's international competitiveness. As you know, most of the staples and principles of the 20th century design have come to us directly from one art school, the Bauhaus. The Bauhaus, of course, was not an American institution. We simply inherited many of its benefits, economic benefits when Hitler closed the school and the faculty fled here. Such a windfall is not likely to reoccur.

If the 21st century is going to be made in America, it has to be designed in America. As a first step, postgraduate art and design studies must be specifically included in the budget's graduate fellowship and support programs. Your foresight evidenced by direct support for graduate study in art and design can make a difference.

### PREPARED STATEMENT

Finally, by failing to recognize art as a fundamental discipline by denying art to America's schoolchildren, we diminish both their education and our collective future. This is plainly what has happened and what the Department budget proposes to continue.

I urge you to reconsider and redress this unfortunate state of affairs.

[The statement follows:]

STATEMENT OF DAVID RHODES

Good morning and thank you for this opportunity to address the Subcommittee. My name is David Rhodes and I come before you today to speak for the future of art and design in America. I am the current chairman of the National Assembly for Visual Arts Education, an arts advocacy consortium formed by several like-mined college presidents. I am also president of the School of Visual Arts in New York City, our nation's largest college of art and design.

I'm here to call your attention to the absence of art programs in the proposed Department of Education budget for Fiscal Year 1991. I personally represent more than 7,000 undergraduate and graduate students and all of their concerns but, due to time constraints, I will limit myself to two essential areas that this budget neglects: federal support for basic arts programs in the kindergarten through 12th grade curriculum and graduate study in art and design disciplines.

Unfortunately the proposed federal education budget is far more limited than even these modest remarks. In fact, while the budget pays some lip service to the arts, actual art and design are not mentioned, in letter or in spirit, in the 87 pages of the document. This by now tradional visionlessness comprises nothing less than a continuing tragedy for America's schoolchildren, a denial of fundamental educational rights, and a dangerous oversight in planning America's future.

As usual, the budget specifies several curricular areas with precision, but the visual arts are completely ignored. For example, the language describing the $213 million Magnet Schools program, fails to include the visual arts, source of some of the oldest and most successful magnet programs nationally. Please understand that art has little hope of generating significant local support and funding unless and until the Department of Education sets a new national example. There is little argument concerning the impact and importance of art in elementary and secondary education. Around the nation arts magnet schools are achieving remarkable results across the curriculum and arts-based activities have proven especially effective in reaching children at risk.

Critical support from the Department of Education is required now to help put new art teachers in classrooms and to develop and bring new initiatives to fruition.

Concerning support for graduate and advanced professional study, I would remind you that design is a critical component of America's international competitiveness. As you know, most of the staples and principles of the 20th century design have come to us directly from one art school. The Bauhaus, of course, was not an American institution. We simply inherited many of its aesthetic and economic benefits when Hitler closed the school and the faculty fled here. Such a design windfall will not reoccur. If the 21st century is going to be made in America it must be designed in America. As a first step, postgraduate art and design studies must be specifically included in the budget's graduate fellowships and support programs. Your foresight, evidenced by direct support for graduate study in art and design, can make a difference.

Finally, by failing to recognize art as a fundamental discipline, by denying art to America's schoolchildren, we diminish both their education and our collective future. This is plainly what has happened and what the Department's proposed budget continues. I urge you to reconsider and redress this unfortunate position, and I offer our considerable resources to this end. Thank you.

Senator HARKIN. Now, the testimony is there is no existing authority in the Department of Education for arts education. Is that so?

Mr. RHODES. The question is language. In other words, what I am asking for is, for example, if you take a look where there is authorization for areas of need—of national need, and my concern is, or my belief is these are areas of national need, particularly with respect to design, and that if they are included as such, so that instead of thinking only mathematics, science, and engineering, one thinks mathematics, science, engineering, and design, that is a rather short step, or easy step to make to begin a process which is much more far reaching, we think, over time. That would be one thing.

Also, for example, there are authorizations for assessments. The arts are excluded from inclusion as areas that ought to be assessed. Assessments in the arts would probably be difficult and expensive. There are not standardized tests, but it is certainly would be something that would be worth doing and probably would not be terribly expensive.

Senator HARKIN. Thank you very much for being here. We appreciate it.

## STATEMENT OF ROBERT SCANLON ON BEHALF OF THE JOINT COUNSEL OF ALLERGY AND IMMUNOLOGY

Senator HARKIN. Next is Dr. Robert Scanlon, Joint Counsel of Allergy and Immunology.

Senator HARKIN. You are at Georgetown?

Dr. SCANLON. Yes, sir.

Senator HARKIN. Please proceed.

Dr. SCANLON. I am codirector of the Allergy Clinic at Georgetown, and codirector of the training program of allergy and immunology. I also have a practice in Bethesda, and as you mentioned, I do represent the Joint Council of Allergy and Immunology, which represents 3,200, approximately, allergists and immunologists, basic researchers throughout the country.

We first wish to express our appreciation to be able to testify here today. We also wish to acknowledge and recognize the foresight of Congress, in the past in funding numerous basic biomedical research programs, which have resulted in significant successes. And these advances have been in immunology and basic research, in AIDS vaccines and rheumatoid diseases and conditions that affect 40 million Americans, namely asthma and allergy.

Now, unfortunately—or fortunately, as the advances have continued, so have the needs for funding, particularly in training and in funding for research grants. I would like to highlight two areas that the NIAD and the NHLBI feel are important but have not been successful in funding.

One is an asthma program targeted at inner city asthmatics who are at risk for asthma, and it is an educational and a research program, and the other are for two centers, which are cooperative research centers for asthma and allergy for one, and for immunology in the other. And the basic idea behind these centers is to allow interfacing between basic research scientists and the clinicians, which basically is an excellent idea.

As far as funding, the joint council wishes to support the funding request by the Ad Hoc Committee on Biomedical Research, namely $9.2 million as compared to the President's $7.9 million.

Now this funding, I think, as you know, would allow for 33 percent awards for competing grants. And that would include full restoration of funds rather than elimination by downward negotiation. And this compares to the 22 percent this year, which also includes downward negotiations. And it compares with the 45 percent which would be considered optimal.

## PREPARED STATEMENT

I wish to close by saying that we all agree. And I will say something about which we all agree, and that is that we are all interested in good health. And I see from the many testimoneys today, that there are many facets of good health, and I realize your committee and yourself have difficult tasks, to say the least, in appropriating. The work done by all of these groups, and by NIH, certainly will pay off in the long run with excellent health for the American people.

Thank you for listening.

[The statement follows:]

# STATEMENT OF DR. ROBERT SCANLON, ON BEHALF OF THE JOINT COUNSEL OF ALLERGY AND IMMUNOLOGY

Thank you Mr. Chairman. My name is Robert Scanlon. I am a Clinical Professor of Pediatrics and the Co-Director of the Allergy Training Program at Georgetown University Medical Center, and a Member of the Board of Governors of the American College of Allergy and Immunology. I am here today testifying on behalf of the Joint Council on Allergy and Immunology (JCAI) and I would like to request that my written statement be placed in the record.

The JCAI is a professional society which represents the interests of the American Academy of Allergy and Immunology, and the American College of Allergy and Immunology. We represent over 3,200 physicians, both clinicians and researchers in allergy and immunology, working to ameliorate the suffering of the 35 million Americans who suffer from an allergic or immune disorder.

Before I proceed with my statement, I would like to thank the Chair and the Members of this Committee for the opportunity to testify today. I would also like to express the appreciation of the JCAI for all of this Committee's support of medical research programs in the past. Had it not been for the support of the Congress over the past decade, our research programs would be experiencing substantially more difficulties than they currently are.

In fact, I would like to stay on the subject of medical research and introduce the three important aspects I will discuss today: funding of research, particularly basic research; training; and, the use of animals in research. In the view of the Joint Council, these are the three most critical needs for research in allergy and immunology, as well as in biomedical research more broadly.

## Background

In the field of allergy and immunology, funding by the National Institutes of Allergy and Infectious Diseases (NIAID) has yielded significant advances and supported timely initiatives with the potential to alleviate the suffering of millions of Americans and reduce health care costs. Recently, for example, basic research has yielded important findings in our understanding of the genetic control of the immune response, the function of cytokines in allergy and inflammation, the identification of synthetic molecules capable of disrupting replication of the influenza virus, and new insights into the structure of the AIDS virus that can be targeted for development of new anti-viral agents and/or a vaccine.

An estimated 40 million Americans suffer from allergic diseases. Ten million of these have asthma -- one third of whom are under 18 years of age. Recently, the prevalence of childhood asthma, as well as associated hospitalizations, have been increasing in the U.S., especially among urban minorities. To address this serious problem, the NIAID has started urban asthma clinical trials examining treatment methodologies.

In another area affecting children, NIAID researchers have developed a new type of acellular pertussis vaccine with the potential to reduce the high rate of adverse reactions associated with the current vaccine, which has been in use since 1945.

Such advancements all derive from investment in basic research that is the core of our research efforts. It provides the foundation upon which all other research efforts are built. However, recent funding constraints have been so severe that many scientists believe that we will soon lose pace with our competitors, and lose our preeminence in this field. It is important to point out that several of our competitors spend a larger percentage of their GNP per capita on medical research than the United States currently does.

## Basic Research

This year, NIAID expects to fund 1,624 non-AIDS research grants, which includes funding of only 22% of approved competing grant applications. Then, researchers who do get funded still have to contend with "downward negotiations" in their research grants. As you know, they are actually cuts, equivalent to 10-14% of the grant award up front, and additional cuts in the out years. The President's budget for FY 91 does not call for any increase in the number of non-AIDS grants or even for full funding of research grants.

The Joint Council would like to stress the importance of strengthening the non-AIDS basic research portfolio of NIAID. Right now, a multitude of basic research opportunities remain unfunded, in areas ranging from the basic regulation of the immune system, to the immunology of infectious disease, to immunosuppression and transplantation. These and other priority research areas have been expertly outlined by the NIAID Task Force on Immunology and Allergy in its draft report, which we recommend to this Subcommittee.

The Joint Council supports the recommendation of the Ad Hoc Group for Biomedical Research calling for $9.2 billion for NIH as the minimal level of funding for NIH's research programs. Funding of NIH at the level recommended by the Ad Hoc Group will allow for funding of 33% of approved competing grants at NIAID and will allow full restoration of grants, i.e., no downward negotiations. However, you should be aware that this is still substantially below the professional judgement of researchers in the field which calls for funding rates of 40-45%.

In addition, the JCAI would like to provide our strong support for a few specific NIH initiatives. The Asthma and Allergic Disease Cooperative Research Centers and the Cooperative Research Centers for Immunologic Diseases are two of the NIAID Research Centers which were instituted to promote close coordination between clinical investigators and basic researchers. However, the President's Budget did not provide for full funding or any expansion of these critical programs. The JCAI is requesting that these Research Centers be fully funded by direct appropriation and that the reductions by downward negotiation be restored. This too is in keeping with the recommendations of the Ad Hoc Group to fully fund existing centers.

JCAI's other high priority program area is asthma research and education--particularly efforts targeted towards prevention and intervention in urban and minority populations at increased risk. NIAID needs new money in FY 91 to provide for targeted research on interventions for asthma morbidity in inner city children. In addition, NHLBI supports broader asthma education efforts and needs new money to focus on the populations at highest risk. The Joint Council is requesting additional funding to support each of these critical initiatives in asthma research and education.

### Training

Next, I would like to thank you for the restoration of the training budget in the 1990 appropriation. Good science requires adequately trained people and the U.S. needs all the scientists we can produce. As you know, there are still many needs in this area. NIH funding at the level recommended by the Ad Hoc Group would allow for full funding of the existing research training positions at NIH.

Animal Use in Research

Finally, I can not overemphasize the importance of animals in biomedical research today. History reminds us of the significant role that animals have played in the development of medical knowledge and treatments--classic examples like polio, penicillin, and insulin come quickly to mind. Others are more current. Without decades of research on retroviruses in animals, we still might not have identified the virus that causes AIDS, the human immunodeficiency virus. The tough question is predicting the next major advance that will come from animal research -- if such progress is allowed to occur.

This Subcommittee is well aware of the passions surrounding this issue, but I want to let you know that, while the biomedical research community has maintained a largely rational and scientific demeanor throughout this debate, we will not be quiet any longer. As you know, some animal rights activists have taken matters into their own hands to the degree where state-of-the-art research facilities are destroyed, professional scientists demoralized, and research grants, possibly funded through the foresight of this Subcommittee, are wasted.

Let me assure you that the JCAI advocates the legal and humane treatment of research animals and the use of alternatives where they are both appropriate and available. However, as much as we would like to be able to rely completely on alternatives to the use of animals, the hard reality is that such alternatives simply do not exist in many of the most critical and promising areas of medical research. It is imperative that researchers continue to have the support of the Congress. The safety of research animals, researchers, and the integrity of biomedical research itself require the strong support and protection of the Congress to promote the advancement of science. In that regard, the Council applauds your support and successful passage of the Heflin bill in the last session of Congress. When enacted, the bill will go a long way towards providing the legal protections so necessary in the crucial area.

Senator HARKIN. Dr. Scanlon, thank you for being here today. I do not know if you heard my statement earlier today about—that compared military research—how much—24 months.

Dr. SCANLON. Twenty-four months more in military research than in biomedical research since the second war. That is amazing.

Senator HARKIN. It is mind boggling when you think about it. Well, thank you very much, Dr. Scanlon. We will do our best. The $9.2 million is something we will try. NIAID was $832 million last year, requested at $886 million this year. What is being recommended for NIAID?

Dr. SCANLON. For the NIAID? I think it is about $880 million. I think that is the figure that I had read.

Senator HARKIN. Thank you very much.

## STATEMENT OF ELLEN STRACHOTA, HEAD, DIVISION OF NURSING, GRAND VIEW COLLEGE, ON BEHALF OF THE TRI COUNCIL FOR NURSING

Senator HARKIN. Well, we started with Iowa, and by gosh, we end with Iowa.

Dr. Strachota, thank you very much for being here. Dr. Ellen Strachota, head of the Division of Nursing at Grand View College in Des Moines. It is good to see you.

Dr. STRACHOTA. It is indeed a privilege to have this opportunity to testify this morning or this afternoon now, and it is on—I am here with the considered judgement of the Tri Council of Nursing. And I am talking levels of Federal support necessary for the Nursing Education Act, and also the nursing research for fiscal year 1990.

The Tri Council recommendations are included in the brochure that I have attached to my testimony, which I request to be part of the record. The Tri Council represents over 300,000 nurses and nursing educational institutes. And as an Iowan, I really appreciate the kind invitation to come at the last minute to be heard here today.

Thanks in part to the Nursing Education Act funding and this subcommittee's support—and Senator Harkin, the future looks brighter for nursing to play a central role in meeting America's vital health care needs.

Enrollments have been increasing in nursing education programs in the last year. And there has been a decrease in nursing vacancies in some of the metropolitan hospitals, but all is not well in nursing. There are still some troubling events that have threatened health care development.

The Department of Health and Human Services has directed nursing student loan program repayments to the loan guarantee for defaulting health professions other than nursing instead of recommitting the funds to nursing schools or students.

In West Virginia, schools of nursing will be unable to admit over 200 qualified applicants because of faculty shortages.

About 20 Texas associate degree nursing programs sought waivers from the State requirement of master's degree prepared faculty because of shortage of nurses with master's degrees. And this is because there is no funding to help get the advanced nursing education.

Moderate to severe shortages of registered nurses have been reported in rural hospitals, nursing homes, and home care. And the National Center for Nursing Research was able to support only about 25 percent of the approved projects.

America needs upgraded nursing skills to match technological advances, to serve an increasing elderly population, increased number of people with chronic illnesses.

This morning we have heard a lot of testimony about some of these chronic illnesses, and we believe that nursing is the center point of this and needs to be funded so that we have nurses to help care for individuals.

The Tri Council requests $69.05 million for nursing education, and we do realize that is a substantial sum, but it is slightly more than one-half of the full authorization of the Nurse Education Act, and only about two-thirds of the cost of the C-5B aircraft. So the following are examples of what is included in the Nurse Education Act program.

One portion is the advanced nurse education, and that is a source for nurse administrators, faculty, researchers—those people that we need to advance the science of nursing. An example of what the funding was used for was a LaSalle University community health project, which was designed to attract working and minority, specifically, for nursing. The Tri Council recommends funding at the $17.2 million.

Other projects include special projects that include innovative projects to educate displaced workers, to also provide continuing education up the ladder of nursing. As you well understand, we have nurses that are prepared at the beginning level, licensed practical nurse, even some at the nurse aid level, and we need to facilitate their movement up to become registered nurses, so that they can care for the complex illnesses that we have with us today.

We also need money for professional nurse traineeships, where we could have money for these nurses needed at the masters and doctoral levels. Presently, we are—there are scholarships and stipends for over 5,400 nurses. And we need that to continue or be enhanced.

The nurse practitioner and certified nurse midwife program has served a valuable function throughout our history in nursing. At present, we support—the fiscal year 1989—this program supported 685 nurse practitioners and 191 certified nurse midwives in such places as Kentucky and at the University of Washington Family Nurse Practitioner Program for the undeserved.

We have nurse anesthetists and loan repayments, by which undergraduate students can get either scholarships or loans on which then they can serve in undeserved areas. They can practice and some of the loan or their scholarship—they only get the scholarship and the repayment is by serving in rural areas, public health, Medicare, Medicaid facilities.

And then there is also the National Center for Nursing Research. While the Nurse Education Act is critical for nursing education, and, of course, it is where I really belong, my heart and love, it is also very important that we have adequate funding for nursing center, for nursing research. That is where the science of nursing, where we are developing. Dr. Ada Sue Henshaw has been very active and very viable in what we are doing with increasing projects there. Presently there is about eight projects being funded at—in Iowa, that includes projects on nurse retention, Alzheimer's, healing bed sores, successful dieters, elderly skin project. I think when you were at the University of Iowa, you were able to see some of the actual work that is being done through the NCNR.

We are requesting—Tri Council requests $42.5 million for the NCNR. Although the Tri Council would have testified in support of full funding, we feel that even our worthy mission must be tempered by balance and concern for the deficit, with future health system demands.

We have sought funding only for the muscle and bone to carry on our programs, and respectfully request the support of this subcommittee for funding Nurse Education Act programs at $69.05 million and the NCNR at $42.5 million.

### PREPARED STATEMENT

I would like to take this opportunity to thank you again for all the support you have given nurses, both in the Nation and specifically in Iowa, and that I would be more than happy to answer any questions.

[The statement follows:]

# STATEMENT OF ELLEN STRACHOTA, HEAD, DIVISION OF NURSING, GRAND VIEW COLLEGE, ON BEHALF OF THE TRI COUNCIL FOR NURSING

I am Ellen Strachota, RN, PhD, Head of the Division of Nursing at Grand View College in Des Moines, Iowa. I am president of Iowa Nurses' Association, the Iowa Association of Colleges of Nursing, and a member of AACN. My testimony represents the considered judgement of the Tri Council for Nursing on levels of federal support necessary for nursing education and research for fiscal year 1991. The Tri Council's recommendations are included in the brochure attached to my testimony which I request be made part of the record. The Tri Council includes the American Association of Colleges of Nursing with over 410 members offering four year and graduate nursing education, the American Nurses' Association representing 200,000 registered nurses through 53 constituent state nurses' associations, the National League for Nursing with 1,500 registered nurse educational institutions and 15,000 individual members, and the American Organization of Nurse Executives with 5,300 nurse executives and managers. As an Iowan, I especially appreciate the Chairman's kind invitation to be here today.

Thanks in part to Nurse Education Act funding and this Subcommittee's support, the future looks bright for nursing to play a central role in meeting America's vital health care needs. Enrollments in baccalaureate nursing programs for the 1989-90 academic year were up 5.8% over the previous year, and staff nursing vacancies in many metropolitan hospitals were dropping toward 10%. New advertising campaigns and a realization of the desirability of nursing careers are attracting students to the profession. And the Second Advisory Committee on Rural Health recognized that non-physician providers can furnish health services as good as or better than physicians at less cost. Troubling incidents, however, threaten future positive developments:

- The Department of Health and Human Services has directed Nursing Student Loan Program repayments to a loan guarantee for defaulting health professions (other than nursing) instead of recommitting the funds to nursing schools or students;
- In West Virginia, Marshall University's School of Nursing will not be able to admit 134 qualified generic baccalaureate applicants, and West Virginia's BSN program will turn away 37 qualified applicants in 1990 because of faculty shortages due to inadequate funding;
- About 20 Texas community colleges with associate degree nursing programs sought waivers from a state requirement of master's degree prepared faculty because of a shortage of nurses having that degree;
- Moderate to severe shortages of registered nurses have been reported in rural hospitals, nursing homes and home care; and
- The National Center for Nursing Research (NIH) was able to support only about 25% of the projects found deserving of funding by peer review panels.

A disappointment but not a surprise was the Administration's budget proposal to eliminate most funding for nursing education. This Draconian approach fails to recognize the need for upgraded nursing skills to match technological advances in serving an increasingly older population and those with chronic or incurable illnesses. **While the $69.05 million for nursing education sought by the Tri Council is a substantial sum, it is slightly more than half the full authorization for the Nurse Education Act and only about two thirds the cost of one C5B aircraft. The following are examples of the Nurse Education Act programs outlined on the attached brochure:**

**Advanced Nurse Education** - A geriatric/gerontological nursing project at the Medical University of South Carolina focussing on recruiting, retaining, and graduating minority and disadvantaged students resulted in 3 to 4 job offers per graduate. A neonatal nursing program at the University of Pennsylvania prepares nurse clinicians for service in acute care hospitals, the home environment and high risk follow up clinics. And a La Salle University community health nursing project designed to attract working and minority students focussed on underserved populations and areas. ANE programs are the source of nurse administrators, faculty and researchers. ANE supported 100 awards in FY89, but was sharply reduced in FY90. **The Tri Council recommends $17.2 million for FY91 for Section 821.**

**Special Projects/Disadvantaged** - Averaging $125,000, 75 special projects (Sec.820) and 21 special projects for disadvantaged (Sec.827) averaging $175,000 were funded in FY89. A transplant care project at the University of Texas Health Science Center at Houston supports two faculty and ten students for an award of $85,177. Other innovative projects train displaced workers as nurses, provide continuing education (even to rural areas by satellite), and career ladders to help licensed practical nurses become registered nurses. **The Tri Council asks $14.8 million for Sections 820 and 827.**

**Professional Nurse Traineeships** - In FY89, 192 awards provided $12.6 million for scholarships and stipends to over 5,400 master's and doctoral students, including some part time students. **The Tri Council recommends $15.5 million for Section 830.**

**Nurse Practitioners/Certified Nurse Midwives** - The Frontier Nursing Service prepares nurse-midwives to manage care of women in all phases of childbearing in rural areas of Kentucky.

Graduates of the University of Washington's Family Nurse Practitioner master's program serve an indigent and underserved population of Asians and Native Americans. In FY89, this program supported 685 nurse practitioners and 191 certified nurse-midwives. **The Tri Council seeks $15.4 million for Section 822.**

**Nurse Anesthetists** - Because of lower training and service delivery costs, nurse anesthetists have become the preferred choice in many rural hospitals. In FY89, this supported 59 programs. **Tri Council asks $1.8 million for Section 831.**

**Undergraduate Scholarships** - This program provided $1.3 million for 400 students in FY89, who will have at least a two year payback service obligation in a nurse shortage area upon graduation. The expansion of possible payback sites includes about 6,000 public, rural, Medicare/Medicaid and VA facilities. **Tri Council recommends $3.35 million for Section 843.**

**Loan Repayment** - Nurses can repay up to 85% of their nursing student loans by agreeing to serve in a nursing shortage area. **Tri Council asks $1.0 million for Sections 836,837.**

**National Center for Nursing Research** - While the Nurse Education Act is critical to nursing education, adequate funding for the National Center for Nursing Research at the National Institutes of Health is essential for the science of nursing. Of 264 competing (new) grant applications received by NCNR in FY89, 199 were approved, but only 50 could be funded. 80 non-competing (continuing) grants were awarded in FY89. NCNR focuses nursing science on priority issues of mothers and low birthweight infants, HIV infection, longterm care of older people, symptom management, health promotion, technology dependency, nursing resources and quality of care, and information systems. NCNR supported grants in Iowa include a nurse retention project, two alzheimer's project, a healing bed sores project, a successful dieter's project, and an elderly skin dryness project. Using biological, behavioral and social science, nursing research combines improving cost effectiveness and outcomes with sound methods of patient care. **Tri Council seeks $42.5 million for NCNR.**

Although the Tri Council could have testified in support of full funding, we feel that even our worthy mission must be tempered by balancing concern for the deficit with future health system demands. We have sought funding only for the muscle and bone to carry our programs, and respectfully request the support of this Subcommittee for funding Nurse Education Act programs at $69.05 million and NCNR at $42.5 million. Thank you for giving the Tri Council the opportunity to be heard. I would be happy to answer your questions.

The Tri Council is:

**American Association of Colleges of Nursing**, Washington, D.C., with over 410 members offering four year and graduate nursing education programs.

**American Nurses' Association**, Kansas City, MO, representing 200,000 registered nurses through 53 constituent state nurses' associations.

**National League for Nursing**, New York, NY, with 1,500 registered nurse educational institutions and 15,000 individual members.

**American Organization of Nurse Executives**, Chicago, IL, representing 5,300 nurse executives and managers.

**TRI COUNCIL FOR NURSING FUNDING RECOMMENDATIONS FOR FISCAL YEAR 1991**
**(Tri Council priorities in bold)**

[All figures are in millions of dollars]

| NURSE EDUCATION ACT PROGRAMS | FY 90 (Actual) | FY 91 Tri Council Requests | FY 91 NEA Authorization | FY 91 Administration Budget |
|---|---|---|---|---|
| **Special Projects/** (Sec. 820)<br>**Disadvantaged** (Sec. 827) | 12.9 | 14.8 | 20<br>5 | 0<br>5 |
| **Advanced Nurse Education** (Sec. 821) | 12.9 | 17.2<br>(FY 89 levels) | 20 | 0 |
| **Professional Nurse Traineeships** (Sec. 830) | 13.5 | 15.5 | 16.0 | 0 |
| Nurse Practitioners/Certified Nurse Midwives (Sec. 822) | 13.4 | 15.4 | 21 | 0 |
| Nurse Faculty Traineeships (Sec. 830 (b)) | | 0 | 1.1 | 0 |
| Nurse Anesthetists (Sec. 831) | 1.1 | 1.8 | 1.8 | 0 |
| Loan Repayment (Sec. 836, 837) | 1.0 | 1.0 | 5.0 | 0 |
| Undergraduate Scholarships (Sec. 843) | 2.9 | 3.35 | 30.0 | 0 |
| TOTAL | 57.7 | 69.05 | 119.5 | 5 |
| FOR NURSING RESEARCH | | | | |
| **NATIONAL CENTER FOR NURSING RESEARCH (NIH)** | 33.5 | 42.5 | Not Applicable | 35.127 |

Budget Function 550 Health

2/28/1990

NURSING: KEY TO IMPROVED OUTCOMES, COST EFFECTIVENESS AND CARE.

The Nurse Education Act means federal support to:

Individuals for:

* Disadvantaged students
* Undergraduate scholarships for those in need
* Low interest student loans with 10 year repayment

Institutions for:

* Innovative health care projects and practice settings
* Skills upgrades and continuing education
* Attracting and retaining skilled nurses

Individuals and institutions for:

* Nurse educators, administrators and researchers of the future
* Nurse practitioners and nurse midwives
* Nurse anesthetists

Nurse Education Act programs fund:

**Special Projects**: Creative nursing focus on special and pressing health concerns - aging (preventive, acute and long term care training) and geriatric education; rural health; satellite delivery of education; displaced worker education; continuing education; training, and skill upgrades to meet changes in health technology and nursing practice; recruitment, retention and efficiency of nurses in hospitals and home or long term care.

**Disadvantaged Backgrounds**: links to attract and keep disadvantaged students in nursing education - support for recruitment and retention of students, stipends, faculty training, career ladder options for licensed practical and vocational nurses.

**Advanced Nurse Education**: Supports accredited college master's and doctoral programs which are essential for nursing's future clinical specialists, educators, administrators, and researchers - today's investment to ensure quality health care for tomorrow.

**Professional Nurse Traineeships**: (The individual support side of the Advanced Nurse Education coin) - grants to registered nurses in nursing master's and doctoral programs, including part-time students, without which many nurses would be unable to expand their capabilities to meet America's complex health care needs.

**Nurse Practitioner/Certified Nurse Midwife**: Institutional and individual educational support to produce these advanced nurse clinicians often serving as primary caregivers in rural/community health centers and public health facilities. Recipient obligated to a month of public service for each month of support.

**Nurse Anesthetists**: Program and individual assistance for registered nurses to become nurse anesthetists.

**Undergraduate scholarships**: tuition and fees for financially needy (with preference to socially or economically disadvantaged) full time students seeking a first nursing degree. Recipients are obligated to work a minimum of two years in an eligible health facility.

**Nursing Student Loan Program**: Loans of up to $2500 for each of the first two years and up to $4000 for third, fourth and graduate years (with a cap of $13,000) for financially needy nursing students at a 5% interest rate with a ten year repayment which can be deferred. Almost 450,000 loans have been made, and the money is recirculated to new students as it is repaid by graduates. The last appropriation was made in FY83 and about $245 million is outstanding in current nursing student loans. No new money is being sought this year, but existing funds must be preserved for nursing student use.

**Loan Repayment for Shortage Areas**: Nurses can repay up to 85% of their Nursing Student Loans by agreeing to serve for at least two years in an area/facility having a nursing shortage.

**Nurse Faculty Traineeships**: Grants to nursing schools for post baccalaureate faculty fellowships. The Tri Council seeks no appropriations for this program.

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Not part of the Nurse Education Act but essential for the scientific advancement of nursing practice and patient care is:

**The National Center for Nursing Research**: Represents nursing science concerns as part of the National Institutes of Health by performing intramural (within NIH) and extramural (grants to researchers in schools of nursing) research on NCNR priorities of low birthweight: mothers and infants; HIV infection; long term care of older people; symptom management; health promotion; technology dependency; nursing resources and quality of patient care; and information systems standardization. Of 264 competing (new) grant applications received by NCNR in FY89, 199 were approved, but funds limited awards to only 50. Non-competing (continuing from past awards) grants were 80 in FY89. Nursing research, using biological, behavioral and social sciences, increasingly combines improving cost effectiveness and outcomes with sound methods of patient care.

Senator HARKIN. Thank you very much, again, for being here and taking the leadership role in getting adequate funding for all of these different programs. I just want to make sure I understand this completely here. In fiscal year 1990, we had a total of $57.7 million.

Dr. STRACHOTA. Correct.

Senator HARKIN. Now, last year for NIH, for the National Center for Nursing Research, we had $33.5 million.

Dr. STRACHOTA. Correct.

Senator HARKIN. The administration has requested $35.1 million, a reduction.

Dr. STRACHOTA. No; it is an increase.

Senator HARKIN. Oh, $35 million. I am sorry. It is $35.1 million, and you are asking for $42.5 million.

Dr. STRACHOTA. Correct.

Senator HARKIN. And for the total on all these other programs that you just went through, for the faculty traineeships, loan repayment, $69.5 million.

Dr. STRACHOTA. Correct. And the administration had $5 million in their budget. They zeroed out like they did last year.

Senator HARKIN. That is what makes it tough. When you start from zero, it always makes it tougher to try to get up to where we need to be. It looks like for nurse anesthetists you are asking for the full level. Professional traineeships, about the full level. For the undergraduate scholarships, it seems to me you are asking for the least amount in proportion to what the authorization level is.

Dr. STRACHOTA. Correct.

Senator HARKIN. Is there a reason for that, or is that just the way it falls out in terms of your priorities?

Dr. STRACHOTA. It is probably the way it falls out in our priorities. We believe that we need people to educate those undergraduate students, as well as the undergraduate student scholarships. And there other avenues by which they can get some funding for the scholarships.

Senator HARKIN. There are other resources and things like that?

Dr. STRACHOTA. Not enough. As ever, there is never enough of anything, but——

Senator HARKIN. Well, we will see what we can do again this year. Well, we got it up from zero to all these other figures last year.

Dr. STRACHOTA. Correct. The major one that went down last year was the advanced nurse education. That went down below, and if you notice these a fairly good size hike asked in that for the $17.2 million, but that is to regain the level, fiscal year 1989 level.

Senator HARKIN. Well, I hope we get our correct budget allocation from the Budget Committee. But you have a lot of support from this committee, not only from me personally, but other members of the subcommittee and the full committee.

And, again, we recognize that if we are going to meet our health care needs in this country, we are just going to have to put more emphasis on the whole broad spectrum of nursing in America, making sure that we have nurses who are well educated, the career ladders that you talked about. I really do.

I believe all the problems that we are confronted in terms of long-term care that is facing us, the nurses are going to play a big role in helping us solve that problem. Rural health care, again, nurses can play a big part in helping that problem. And utilizing nurses more than we have ever utilized them in the past. Of course, with that utilization must go the necessary support services, education services and the compensation, and we will see what we can do to get it in there.

## CONCLUSION OF HEARINGS

Thank you for being here. I would like to thank all the witnesses who have appeared before us with regard to the proposed fiscal year 1991 budget request.

Today's testimony completes our hearings, and the the subcommittee will now recess, subject to the call of the Chair.

[Whereupon, at 1:15 p.m., Thursday, March 29, the hearings were concluded, and the subcommittee was recessed, to reconvene subject to the call of the Chair.]

# Material Submitted Subsequent to Conclusion of Hearings

[CLERK'S NOTE.—Additional material was received by the subcommittee subsequent to conclusion of the hearings. The statements will be inserted in the record at this point.]

# DEPARTMENT OF LABOR

## STATEMENT OF KAYE R. KIDDOO, DIRECTOR, CALIFORNIA EMPLOYMENT DEVELOPMENT DEPARTMENT

The federal budget proposes a cut of $56 million to the Job Services (JS) Program. However, California proposes that Congress approve a minimum level of $850 million for the Employment Services (ES) Program.

California is concerned about the proposed federal reduction of $56 million in the State's ES Program. As you know, these resources are used to fund the public employment service which is a nationwide system providing no-fee employment services to individuals who are seeking employment and employers who are seeking workers.

Certainly, it is the desire of citizens, public officials and corporate leaders, that all Americans be employed, productive and self-supporting. At the same time, there are employers who want qualified workers to meet their labor shortages. The ES Program bridges this gap by matching unemployed workers and employers seeking workers. The Employment Services knows the local economy; and now, more than ever, it is critical to match job requirements with available worker's skills.

Additionally, the ES Program is a partner to the Unemployment Insurance (UI) Program, facilitating re-employment for workers collecting unemployment benefits, thus reconnecting workers with the self-respect that employment provides, reducing benefit drawdowns on the State's UI trust funds, and thus keeping employers' taxes down. Through its more than 1,800 local offices and its linkages with businesses, education, training and welfare systems across this country, the ES Program touches the lives of millions of employers and workers every year.

Nationally, the ES Program helped 4.8 million job seekers find jobs and listed more than 7.2 million job openings. In addition, more than 32,000 employers provided guidance to ES as members of Job Service Employer Committees.

Yet, the proposed budget for the ES Program which is used to maintain these critical services is being cut.

The administration's request of $722.6 million to fund ES programs in State Fiscal Year (SFY) 1991 is inadequate. For your information, over half the states now are supported by funds approved by their state's Legislature to keep the ES Program afloat. For the past six years, the federal ES allocation has not provided sufficient resources to maintain California's staffing level of 1,433 personnel years, nor has it kept pace with the increased number of employers and job seekers. To maintain this critical labor exchange function, California has supplemented the ES Program from State resources by more than $16 million (FFY 1990). If this $56 million reduction to ES is approved by Congress, it is highly unlikely that California will be able to increase its supplement for this program. Therefore, essential applicant and employer services will be reduced or eliminated.

This reduction of funding will certainly increase employer taxes in all states, including California, to repay UI trust funds for the additional weeks claimed by individuals who are unemployed. Failure to adequately fund the Employment Services Program represents a serious breach of faith with both the unemployed who need our help and the employer community who have more than adequately funded this program through their federal unemployment taxes.
It is our understanding that this program reduction is proposed as a deficit reduction measure. Yet the employer paid Federal Unemployment Taxes are expressly available only for administration of the employment security system. This reduction will rob both the workers and the employers, who are paying the taxes for quality services. Employers should get the services they have paid for, and the emerging economy needs a viable employment service program that can connect workers with jobs expeditiously, if the nation wants to continue to hold our competitiveness.

Therefore, California recommends an appropriation of $850 million for the ES Program.

## STATEMENT OF THE DISPLACED HOMEMAKERS NETWORK

The Displaced Homemakers Network urges the Subcommittee on Labor, HHS, Education and Related Agencies to appropriated $5 million for Department of Labor Women's Bureau. The Women's Bureau, as the only federal agency with the mandate to address the needs of working women, must have the resources to develop programs and policies that can meet the challenges that lie ahead.

It was during the mid-1980's that much of the information and data about Workforce 2000 was developed by the Department of Labor and others. Perhaps the most outstanding finding of the research conducted on the future workforce is the critical role women will play.

Projections indicate that between now and the year 2000, almost two-thirds of the new entrants to the workforce will be women. By 2000, women will comprise nearly half of the nation's labor force; 80% of women ages 25-54 will be working. The traditional pool of potential workers-- young, white and male-- will continue to shrink. Women of color and mid-life and older women will have to be prepared to fill business and industry's needs.

Already employers have begun to turn what they refer to as "nontraditional" workers. Displaced homemakers-- women who have lost their primary source of income and are forced to enter or re-enter the workforce-- are among those who employers will have to depend on to step into new and vacant positions. Despite the large influx of women into the paid workforce, early findings from a soon-to-be released study of the Current Population Survey indicate that the number of displaced homemakers has continued to rise. These women, whose employment and training needs are unique due to their age and lack of paid work experience, must have access to strong programs and resources in order to successfully enter and remain in the workforce.

Ensuring that women have skills and the necessary support systems which can contribute to America's economic well being and to the economic security of their families is imperative. The fact that the future workforce depends on productive participation of women has many implications for employers as well as for the women themselves. The future of the American economy dictates that for employers it cannot be "business as usual," and for women there must be policies and strategies that assure their ability to be full participants in the workforce.

The Women's Bureau, with very limited resources, has begun to address some of these hard issues. With the establishment of the Work and Family Clearinghouse, the Bureau has begun to look at the complicated issues around child care. Also, through a grant to the Displaced Homemakers Network, the Bureau is supporting technical assistance and training for 1,100 local displaced homemaker programs serving over 300,000 women annually.

But, this is just the tip of the iceberg. There are dozens of issue that the Women's Bureau should be able to address, but cannot without additional resources. Women's employment issues such as adult dependent care, health and safety, training to move women from welfare to self-sufficiency, benefits, promotions and diversity in the workplace also need the Bureau's attention.

We urge you to increase the Women's Bureau appropriation from $1.7 million in FY1990 to $5 million in FY1991. This is still an extremely modest sum of money given the mandate of this agency. Women are to play a major role in keeping this country competitive. The appropriations of the Department of Labor Women's Bureau should reflect this important charge.

# STATEMENT OF THE AMERICAN ASSOCIATION OF OCCUPATIONAL HEALTH NURSES

AAOHN, the professional association for registered nurses who provide on-the-job health care for the nation's workers, has a specific concern about occupational health nursing which we would like included in Appropriations language for the Occupational Health and Safety Administration.

Four disciplines collaborate and participate in the delivery of occupational health services: nursing, medicine, safety, and industrial hygiene. Occupational health nurses are the largest group of health care providers at the worksite. In fact, AAOHN has documented that more than 60% of our approximately 12,000 members are the sole health care providers at their worksites.

Some roles and functions overlap among the disciplines. However, nursing, as well as the other disciplines, has many independent, autonomous functions which do not require the supervision or oversight of any other profession. Recognizing this fact, the National Institute for Occupational Safety and Health has funded Educational Resource Centers to provide education and training for each of the four disciplines.

Only three of the disciplines are involved in policy making at OSHA: medicine, safety and industrial hygiene. Since 1986, AAOHN has worked toward inclusion of nursing at the policy making level. Language in the FY '89 Appropriations bill (Senate Report 100-399, page 25) directed the agency to hire an occupational health nurse in a policy making position.

A well qualified occupational health nurse was finally hired; initially the position reported to the Director of the Office of Medicine, Directorate of Technical Support. However, for several months now the individual has been reporting directly to the Director of the Directorate of Technical Support.

The individual has attained a great deal of credibility within the agency. In fact, this individual was asked to write the medical surveillance/medical management portion of the ergonomic guidelines for the meat packing industry recently developed by OSHA.

The individual also has had heavy involvement in the development of the bloodborne pathogens standard. For example, this individual coordinated the agenda for two days of the public hearings, including identifying and interviewing witnesses by request of the Director, Directorate of Technical Support. At the request of the standard project officer, this individual reviewed and provided comment in the proposed testimony of Agency expert witnesses.

AAOHN is very concerned to learn that a proposal is being discussed which would once again place nursing personnel under the Office of Medicine at OSHA. This will perpetuate the myth among policy makers, regulators and employers that nurses must report to and are subordinate to medicine. The result of this myth is that companies bear extra cost in hiring physicians to "sign off" on the services provided by nurses and that nurses are prevented from providing services within the full range of their legal scope of practice. The cost issue is of particular concern for all business and industry, but particularly small businesses.

The proposal also has implications for the nursing shortage. The Secretary's Commission on Nursing concluded that a major contributor to the nursing shortage is this same lack of recognition and autonomy. Nurses are leaving the profession and students are choosing other professions at this time of increased demand and need for nursing services.

In summary, occupational health nurses are the largest group of health care providers at the worksite. It is vital that their role and contributions are considered at the policy making level at OSHA.

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## STATEMENT OF THE NATIONAL FEDERATION OF FEDERAL EMPLOYEES

Mr. Chairman and Subcommittee Members:

I appreciate the opportunity to present the views of the National Federation of Federal Employees (NFFE) regarding Fiscal Year 1991 appropriations for the Social Security Administration (SSA). NFFE represents more than 150,000 dedicated Federal employees, many of whom work for the SSA. We are concerned about the field offices having sufficient resources -- personnel, training, overtime monies, furniture, equipment and moving expenses -- to adequately and efficiently provide the service to the public with which the agency is charged.

Over the past few years, resource shortages have resulted in work backlogs, decreased employee morale and restricted numbers of applicants applying for promotions within the agency. What this means to the public is that they are not getting the service they deserve because decisions are delayed, payments at times are not proper, information is not always correct and employees are sometimes curt.

We have seen SSA's staff reduced by some 17,000 to 20,000 employees over the last few years. These employees have been lost through attrition -- including both those leaving the agency to seek other employment and those who were encouraged to leave on early retirement in order for the agency to achieve its downsizing goals. In justifying downsizing, the agency assured Congress, SSA employees and the public that even with downsizing, the agency would be able to provide quality services because of the implementation of the 800 number and increased computer capabilities.

Reality, however, has been quite different from this promise. We have seen a myriad of problems caused by staff reductions and the implementation of the 800 number. We have also not experienced the promised updating of all equipment and computer capabilities as promised. The result of these problems, frankly, has been devastating. .

Downsizing has caused the loss of some of the clerical employees. The result has been that much of the clerical work -- filing, typing, receptionist duties, mail, and the like -- is done by technical and management staff. Unfortunately, this takes needed time away from processing claims and post-entitlement workloads which in turn causes delayed decisions to claimants, incorrect or delayed payments and an overall reduction in the service to the public.

Increased workloads for the remaining employees have caused some employees to be curt with the public because employees know they have to move quickly on to the next phone call, the next claimant, or try to attack the stack of files on their desks. All of this adds to employee frustration reducing their morale even further.

Some of SSA's smaller offices have been forced to close as a result of fewer staff members and the implementation of the 800 number. Thus, there has been a reduction in the number of contact offices across the country. NFFE has found that since the typical SSI beneficiary is elderly, mentally or physically challenged, or a survivor, face-to-face meetings are generally more helpful and beneficial than phone calls. Unfortunately, staff reductions force claimants to travel many miles to reach an office to have face-to-face contact. Furthermore, some offices actually turn away claimants because they cannot handle the extra case load. The public is told to use the 800 number and it can be many weeks before a satisfactory face-to-face meeting actually takes place.

The implementation of the 800 number in 1989 was done prematurely and with little forethought. Employees at the megasites and spike unit telecenters were placed on the job with little training. Many were put on the front line to answer questions over the phone that normally take months of experience to handle properly. Because of the volume of calls, veteran employees and supervisors are not able to be adequate mentors for the new employees as they are answering phone calls. Thus employees are giving out information that they believe is accurate but in fact is not. It is impossible to accurately estimate the extent of the problem. We have seen some of the problems already -- callers are told that no benefits are available until a person is 65; they're told children cannot receive benefits; they're told only that SSI has a disability program. The list goes on and on.

We must point out that these problems do not stem from the employees themselves but rather result from the lack of training and the circumstances under which they work. Congress must adequately fund agencies and expressly mandate that employees be given proper training to properly perform their jobs.

In addition to the problems of downsizing and the premature implementation of a poorly planned 800 number, SSA is suffering from several other conditions. Many employees want to help relieve the pressure and eliminate the backlogs and are willing to work overtime until SSA can hire and train new employees. However, there are no funds for overtime pay. Also employees who are qualified for promotions do not apply because the funds are not there to pay for higher salaries or for moving expenses. The result is that promotion pools offer limited choices and the best candidates do not always get put into higher level jobs.

There is one bright spot, however. The new Commissioner, Gwendolyn King, seems interested both in good service and in improving employee morale. Under her guidance, the agency seems to be beginning to emphasize quality as well as quantity. SSA seems to be looking toward providing the public with true options as to how they can obtain service and encouraging a more in-depth outreach program for SSI. Unfortunately, each of these will require more and better trained personnel, a better physical plant, more basic furniture and equipment and increased travel monies. We respectfully request that Congress appropriate enough money to hire new staff, provide training for the current staff, provide sufficient allocations of overtime money until we have the necessary staff and to provide funds to improve the physical plant and the office furniture and equipment.

Thank you for the opportunity to submit our views. We would be happen to answer any questions you may have.

# DEPARTMENT OF HEALTH AND HUMAN SERVICES

## LETTER FROM MONTO HO, M.D., PROFESSOR AND CHAIRMAN, DEPARTMENT OF INFECTIOUS DISEASES AND MICROBIOLOGY, GRADUATE SCHOOL OF PUBLIC HEALTH, UNIVERSITY OF PITTSBURGH

April 9, 1990

The Honorable Arlen Spector
The Senate of The United States
303 Hart Office Building
Washington, D.C. 20510

Dear Senator Spector:

I am writing to request your support for the Administration's FY 1991 budget request of $21.0 million for the AIDS Education and Training Center program. This program was established over two years ago within the Health Resources and Services Administration of the Department of Health and Human Services. The program has statutory basis within Title VII of the Public Health Service, Section 788A.

I would be grateful if you, as a member of the Senate Appropriations Subcommittee on Health and Human Services, would submit this letter as public testimony in support of the program.

The Pennsylvania/New York Training and Education Center is one of fifteen regional or statewide AIDS Education and Training Centers (ETCs) which were established to provide comprehensive AIDS education to community based health practitioners (particularly physicians, nurses and dentists), to faculty within health professions schools, and to students in medical schools, nursing schools and other health programs. The AIDS ETC program utilizes the expertise of practitioners from the above schools, along with experienced caregivers in the community, to educate more health workers about HIV disease and to increase the clinical skills of those with a basic knowledge of the disease. This expansion is essential to providing appropriate numbers of health care workers for the growing number of individuals with HIV disease.

In the state of Pennsylvania, the Pennsylvania/New York AIDS Education Training Center, a consortium of academic institutions headquartered at the University of Pittsburgh, and funded in September 1988, has trained over 13,000 health professionals in Pennsylvania through a variety of educational programs including specialized seminars and training for physicians, nurses, dentists and other health professionals. In addition the Pennsylvania/New York AIDS Education Training Center has designed a statewide AIDS teleconferencing network for the purpose of delivering AIDS training to rural health professionals throughout the state. As the epidemic grows, the training of rural/non-urban health care providers will be critical in meeting the primary care needs of persons infected with HIV and those with AIDS.

During the first year when there were thirteen AIDS ETCs in operation, the following education services were provided:

## AGGREGATE ESTIMATE FOR 13 ETCs

| PROVIDER CATEGORY | PARTICIPANTS SERVED IN FIRST YEAR |
|---|---|
| PHYSICIANS | 31,976 |
| DENTISTS/DENTAL PROVIDERS | 11,830 |
| NURSES | 59,537 |
| OTHERS | 120,708 |
| SUB-TOTAL OF DIRECTLY TRAINED PROVIDERS | 224,051 |
| TELE-CONFERENCE AUDIENCE | 150,871 |
| TOTAL ESTIMATE OF PARTICIPANTS | 374,922 |

This project is a wise use of federal funds in our estimation. It allows us to plan with some degree of rationality the development of new caregivers. The AIDS ETC network now exists so that the latest advances in research to help patients with HIV disease and to prevent the future spread of the HIV virus can be quickly communicated to the health service community. The numbers of participants speak to the fact that we have been successful in getting educational programs out to the state and cities of America.

The Administration's request of $21.0 million for FY 1991 is an increase in funding from $13.5 million in FY 1990. This increase is necessitated by the expansion during the part year to a total of 15 ETCs nationally. The addition of educational programs will take place during the coming year to key, high case prevalence areas in the United States. Further, more programs will be developed and targeted to help practitioners deal with IV Drug Abuse as it relates to the spread of HIV infection; the many AIDS issues facing minority populations in this country, and expanded clinical education opportunities for advanced AIDS care education. For these reasons, we strongly urge your support of the $21.0 million funding level in FY 1991.

Thank you for your consideration.

Sincerely,

Monto Ho

Monto Ho, M.D.
Professor and Chairman
Department of Infectious Diseases
and Microbiology
Graduate School of Public Health
Professor of Medicine, Microbiology,
and Pathology
Chief, Division of Infectious Diseases
School of Medicine
University of Pittsburgh

## STATEMENT OF THE NATIONAL COUNCIL FOR CHILDREN'S RIGHTS

Chairman Harkin, and Members of the Subcommittee, we appreciate the opportunity to provide testimony to you.

We urge full funding of $4 million for Fiscal Year 1991 under Section 504 of the Family Support Act, to provide for access (visitation) demonstration projects in the states.

NCCR has a nationally prominent Advisory Panel, holds annual conferences, and makes available more than 60 publications to parents and professionals. The aim of our work is assure a child the right to two parents, regardless of the parents' marital status. We seek to reduce the adversarial battling over children after divorce.

We are the group that has urged Congress for several years to provide for access staff, and we have been given an award for convincing Prince George's County, Maryland to hire access mediation staff in that county.

We appreciate the Senate's appropriation of $3 million out of the $4 million that could have been appropriated last year under Sec. 504. The House did not provide a specific amount, but increased research funds for HHS, out of which access money could come. The conference committee also left it up to HHS. HHS has released $1.4 million for access grants this year. We appreciate this funding, but urge that for next year, the Senate fund the entire $4 million. We also ask that you press for the conference committee to hold to that amount.

We urge the funding of access demonstration projects for the following reasons:

1. We should end the era of Forced Away Fathers. Congress has wisely recognized that we should not force fathers out of the house in order for poor parents to collect welfare. We must realize that fathers can be forced away after the marital break-up as well. The $4 million would be a modest incentive to encourage a child's access to two parents.

2. The system needs balance. The Federal Government spends more than $1 billion a year for child support enforcement, but virtually nothing for the other side of the coin--access (visitation). Mental health professionals and judges know there is an interrelationship between custody, support and access. Research indicates that paying attention to access will help resolve support problems.

3. Staff, "800" numbers and ombudsmen are needed. We have child support staff in every county and state to resolve support problems out of court, with a variety of weapons, including wage withholding. liens and interception of tax returns, to enforce support. But only in a few jurisdictions do we have staff, and other remedies to help resolve access problems informally out of court.

4. Prince George's County has proven access enforcement works. In 1986, after the first full year of operation, county officials reported an 80% success rate in resolving visitation problems, at an average time of 1 hour 37 minutes per case, at an average salary cost of $15. per case. Both custodial or non-custodial parents can avail themselves of the visitation mediation staff.

Visitation problems arise in up to 50% of all custody dispositions, according to research by Wallerstein and Kelly; Hetherington, Cox and Cox, and other researchers. We need to pay attention to these problems, and try to resolve them. The result will not only be improvements in parenting, but improved child support collections, as well. For where the parents are around, so are their wallets. Studies show that involved parents contribute more money in child support to their ex-spouses, and also spend more money directly on the child.

Thank you for helping to empower the American family, by supporting resolution of access problems for our nation's children.

## STATEMENT OF THE HEALTH INSURANCE ASSOCIATION OF AMERICA

Mr. Chairman, members of the Committee, I am Arthur Lifson, Vice President of EQUICOR, Inc. We are the fifth largest group health insurance company in the United States, and specialize in managed health care. I also serve as Chairman of the Medicare Administration Committee of the Health Insurance Association of America, the principal trade association of the commercial health insurance industry. In addition to EQUICOR, seven other HIAA member companies help administer Medicare as Part A intermediaries and Part B carriers and have done so since 1966, when Medicare began.*

As intermediaries and carriers our contractor companies discharge the government's responsibility for paying Medicare beneficiaries and providers of service in a timely, accurate and fiscally responsible manner. In recent years, we have worked closely with the Health Care Financing Administration to implement many new payment policies designed to control costs through changes in payment methodology and the detection of fraud and abuse.

We take pride in our long record of professional and efficient performance of these critical program tasks, and in the fact that HCFA and its contractors have one of the lowest overhead costs of any federal government program.

### The FY 1991 President's Budget

The cost to the government of its Medicare contractors operations is largely a function of the number of claims they must process each year.

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*Aetna Life & Casualty, EQUICOR, General American Life Insurance Company, Mutual of Omaha Insurance Company, Nationwide Mutual Insurance Company, TransAmerica Occidental Life Insurance Company, Cooperativa de Seguros de Vida de Puerto Rico, and The Travelers Insurance Company.

While the average administrative cost per claim processed has been lowered nearly every year - and that record of improvement will continue in the future - it is the overall number of claims processed that largely determines the cost of contractor operations in any fiscal year. Likewise, it is the Administration's mistaken assumptions concerning the number of claims to be processed in FY 1991 that will precipitate a crisis in contractor operations, due to insufficient funding, in the last quarter of the year.

The overall funding requested for contractor operations is only 4 percent above the Administration's estimate of costs for the current fiscal year - and that includes 3.3 percent for inflation. The justification offered for such a small increase is that the number of Medicare claims received in FY 1991 is going to be only 0.2 percent higher than the number estimated for this year, and the cost of processing this slight increase in workload will be more than offset by improvements in contractor efficiency.

The Administration is correct in assuming that contractor efficiency will increase - provided there is sufficient funding of the necessary systems improvements and other changes - but its prediction that the increase in claims load will be only 0.2 percent can only be described as unrealistic and unsupported by credible evidence. During the past decade, the annual growth in numbers of claims has averaged 10 percent.

There is nothing in current claims trends to indicate that the claims load will plummet next year. Quite to the contrary, we have every reason to believe that in FY 1991 contractors will receive very close to 600 million claims.

The funding of claims processing and related activities at the level requested by the Administration - despite improvements in contractor efficiency - will result in a backlog of between 45 and 52 million unprocessed claims by year-end. This will be an administrative disaster for contractors and will place them in violation of Medicare's legislated claims payment deadlines. It will generate higher costs in the contractors' beneficiary communications and provider relations work as they struggle under a wave of complaints from beneficiaries, doctors and hospitals. Finally, it will cost Medicare millions of dollars in interest penalties imposed on late claim payments.

The accurate and timely processing of claims is the contractor's most essential task, the performance of which is central to the credibility of the entire program. In past years, the Administration and Congress have cooperated to provide sufficient funds for the necessary work. However, if the the contractors' budget proposed for FY 1991 is enacted, it will result in a breakdown in basic claims processing which may place the stability of the entire program in peril.

Payment Safeguards

In addition to underfunding claims processing, the budget also falls far short in the area of payment safeguards. These medical review, utilization review, audit and Medicare as secondary payer activities will save the program $3.75 billion dollars this year - a return of more than 10 dollars for every dollar expended on them. But much more can be saved. The barely adequate level of funding proposed for safeguard activities next year and will result in the needless waste of hundreds of millions of trust fund dollars in payment of inappropriate or fraudulent claims that would be detected or prevented by a better funded, more vigorous effort. We have not come close to reaching the point of diminishing returns for contractor operations dollars invested in payment safeguards. Appropriate funding could increase trust fund savings to 6 or 7 billion dollars each fiscal year.

Other Critical Tasks Underfunded

The proposed budget would underfund other critical contractor tasks too numerous to mention in this brief statement. For example, in FY 1991, Part B carriers are to implement several initiatives that will make the electronic submission of claims simpler and more attractive for physicians and medical suppliers. These initiatives promise major reductions in claims processing costs, but the effort will produce modest results, at best, at the level of funding the Administration's budget would provide.

Contingency Funding

Contingency funds are usually meant to cover circumstances and costs that cannot reasonably be foreseen at the time a budget is approved. Yet, the Administration has placed in that category the funds necessary to implement the sweeping physician payment reforms and other program changes prescribed by OBRA '89, as well as the funds that will certainly be required to process the predictable FY 1991 claims load. Placing these needed amounts in the contingency category helps satisfy the imperatives of the Congressional budget process, but it also means they cannot be utilized by the Medicare program unless released by the Office of Management and Budget. Based upon OMB's behavior in past years, this will virtually assure that funds are made available so stingily and so late in the year that severe disruptions in contractor operations result.

Medicare law requires the prompt payment of claims. It also requires the implementation of physician payment reforms as scheduled by Congress. The meeting of these mandates is not an uncertainty for which funds should be held in reserve. It is mandated activity with a readily predictable required level of effort. Clearly, the adequate funding of these activities belongs in the contractors operating budget, not in a contingency fund.

Recommendations:

The budget for Medicare contractor operations proposed by the Administration will severely underfund claims processing, payment safeguards, physician payment reform, and provider and beneficiary education activities. To assure timely processing of the nearly 600 million claims expected in FY 1991, the implementation of the OBRA '89 changes as scheduled by Congress, and a level of payment safeguards commensurate with the need to conserve Medicare trust funds, we recommend that the contractors operating budget be increased, at a minimum, by $190 million. We would be pleased to furnish the Committee with details of where those funds are most needed. Most of the necessary funding can be achieved by appropriating for contractor operations the $173 million proposed by the Administration as a contingency fund.

## STATEMENT OF THE SOCIETY OF TEACHERS OF FAMILY MEDICINE

The Society of Teachers of Family Medicine is the professional organization representing family medicine educators throughout the nation. Its membership is comprised of a multidisciplinary group of teachers, including academic-based faculty in departments of family medicine, community hospital based residency training programs, faculty involved in teaching medical students, and practicing family physicians who are part of the teaching faculty in family medicine.

We wish to express our strong support for the Committee to recommend an appropriation of fully authorized levels for Section 780 of the Public Health Service Act in support of family medicine departments and Section 786 in support of family practice residency programs. Last year, with the support of this Subcommittee, Congress appropriated $33.35 million for family practice residency programs and $6.8 million for departments of family medicine. The authorized levels under the current legislation are $40 million for family practice residency training programs and $7 million for departments of family medicine. Thus, appropriations at the fully authorized levels would represent only a modest increase in federal support for this very important program.

Over the past 20 years, the U.S. has mounted a concerted effort to reestablish the family physician as the base of the U.S. health care system. Although great strides have been accomplished, we still have a smaller percentage of family physicians compared to all practicing physicians than any other developed country. For example, 53% of all physicians practicing in Canada are general/family physicians. In the U.S., currently 13% of practicing physicians are family physicians.

As we look toward proposals to assure access to health care for the currently uninsured and underinsured, we must concurrently understand that a greater number of family physicians will be required in order to meet this increased demand. This is a time of great financial difficulty in graduate medical education for family physicians. As two thirds of our nation's family practice residency programs are located in community based hospitals, the general plight of rural and urban public hospitals is intertwined with the fate of family practice residency programs. As public assistance programs have been cut back and the uninsured have turned to these public hospitals, many hospitals have faced the difficult problem of maintaining family practice residency programs. Assistance from the federal government in the form of residency-support dollars has been critical in many situations to maintaining those residency programs.

A similar plight faces departments and divisions of family medicine in our medical schools. As medical education has turned to greater reliance on earned clinical income to support educational activities, family medicine has had great difficulty because its income source is limited. Educational activities to introduce family practice to medical students in our medical schools are often dependent on extramural resources. Federal grants in support of predoctoral and departmental teaching activities in our medical schools are a very important funding priority that will enable us to maintain medical student interest in careers in family practice.

Eleven years ago, the then Departments of Health, Education and Welfare mounted a major effort to look at graduate medical education needs in the U.S. The report of the Graduate Medical Education National Advisory Committee (GMENAC), published in April 1979, predicted a continued deficit in the output of family physicians. Unfortunately, their projections were right on target. In spite of continued federal support, we still are producing too few family physicians for our nation's needs. We still are, at best, in a steady position in terms of total numbers of family physicians, with older physicians leaving the practice due to death or retirement at approximately the same rate as new physicians are being trained in our residency programs. We must maintain our federal support of residency training and academic family medicine activities.

We have appreciated the Committee's support in the past. We look forward to the continued support of the Committee and of the federal government for our family medicine training activities. We are asking that you recommend an appropriation at full authorization levels for Sections 780 and 786 of the Public Health Service Act.

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## STATEMENT OF THE NATIONAL ADOPTION CENTER

I am writing today in my capacity as the founder and Executive Director of two not for profit corporations, the Adoption Center of Delaware Valley (ACDV) and the National Adoption Center (NAC), and as an adoptive parent of three children with special needs. The ACDV operates a regional adoption exchange which serves New Jersey, Delaware and Southeastern Pennsylvania. Licensed adoption agencies register children who are waiting to be adopted and families who are approved to adopt. The ACDV staff suggest "matches" to the appropriate agencies, refers families to agencies for home studies, provides for extensive information and referral service and recruits families for the waiting children. The NAC, through its computerized telecommunications system, the National Adoption Network, links 100 adoption agencies, state and regional exchanges and parent groups across the country. The Network provides a database of waiting children and prospective families, an electronic mail service and bulletin boards to keep members current about adoption practices. Through the Network, members can "match" waiting children and parents. The NAC also conducts an on-going public awareness and recruitment program to benefit the 35,000 children waiting to be adopted in this country.

I will address the need for increased funding for the two special initiatives which are a part of the Adoption Opportunities Act - Post Legal Adoption Services and Minority Children Placements Program, whose appropriation levels for FY 1990 are $1 million and $800,000 respectively. I believe that each of these programs needs to be funded at the $5 million level and the basic program of the Adoption Opportunities Act needs to be continued at $5 million.

## Minority Children Placements Program

The ACDV is currently seeking homes for close to 400 children, 73% of whom are of minority backgrounds. Unfortunately, of the 407 families who are approved to adopt and are registered with us, only 27% are minorities. A closer look at the minority children indicates that 66% are male, 52% are between the ages of 6 and 12, 17% are over age 12 and 45% are members of sibling groups who must not be separated. In addition to these factors, 75% of the children are disabled due to mental retardation, serious learning problems, emotional disturbances or physical limitations. An increasing number of children with multiple problems due to drug use by their mothers are also coming to our attention.

In our seventeen year history we have found that while media recruitment will attract many families, often minority families have many myths about the adoption process and are reluctanct to respond. More intensive, personalized recruitment efforts are needed to reach families through their churches, civic organizations and places of business.

An indication of the interest in and need for providing these recruitment and placement services nationwide is the flood of proposals that were sent to the Department of Health and Human Services in FY 1989. At that time only $500,000 was available for the Minority Children Placements Program and 70 proposals were received totaling $5.25 million.

## Post Legal Adoption Services

In the past the services available to adoptive families ended at the courthouse steps when the adoption of a child was legalized approximately six months after placement. With the adoption of children with special needs, it has been necessary to begin extensive services at the time a child joins a family and extend these services well beyond the time of legalization.

Consider the case of Jason, adopted a year ago when he was nine by Janice, a single nurse from Philadelphia.

> Jason came into foster care when he was two due to physical abuse, suspected sexual abuse and neglect. He was in six placements prior to his adoption and was traumatically separated from his two sisters and brother. By age nine he had developed very verbally aggressive behavior and was physically destructive to himself. He was failing in school and naturally had a very poor self image.
>
> For six months Janice visited him on weekends at the group home in Maryland where he resided before bringing him to live with her. She was fortunate to be working with an agency that has a full range of post adoption services. Janice and Jason immediately entered family counseling together, Jason receives individual therapy and an adoptive parent group was made available to them for support and fun.
>
> Jason is now earning badges in his Boy Scout troop, getting A's and B's in a regular class in school and his emotional problems are now considered mild.

In 1989, the Adoption Center of Delaware Valley found homes for 80 children. Janice and Jason were one of the fortunate families with whom we worked. We estimate that a full range of post adoption services were available in fewer than half of the placements.

Again, looking to the national need for these services, 58 proposals were received by the Department of Health and Human Services. In FY 1989 while the requests totaled $5.8 million, only $500,000 was available for post adoption services to the families who adopt challenging children such as Jason.

## Conclusion

I have addressed the need for minority placement and post adoption services based on past need. If we look to the future, we can see that the need is growing. The House Select Committee on Children, Youth and Families in it report "No Place to Call Home: Discarded Children in America" paints a bleak picture of more children being placed outside their homes, more children experiencing repeat placements, younger children entering out of home placement at an increasing ratio, minority children disproportionately represented in foster care and drug and alcohol abuse contributing substantially to increased out of home placements.

In Philadelphia alone, there was an 81% increase last year in the number of children under the age of one entering foster care. The primary cause was drug abuse by their parents.

We need a continuum of services to assist families to stay together. When that is not possible, we need the best adoption services available to find permanent homes for the children. Once placed the newly created family needs to be supported to cope with the challenges that children with special needs bring with them.

## STATEMENT OF THE RELIGIOUS COALITION FOR ABORTION RIGHTS

The Religious Coalition for Abortion Rights is an organization of thirty-four (34) Protestant, Jewish and other religious bodies. Each of our member faith groups approaches the issue of abortion from its own unique theological perspective. Our member organizations' support of reproductive freedom is integral to our commitment to religious freedom. In our pluralistic society, no one religious viewpoint on the beginning of personhood should be imposed on all Americans by secular law. Americans must be free to make decisions about abortion after thoughtful consideration, based on one's own conscience and religious beliefs and consistent with sound medical practice. It is a violation of religious liberty for government to promote or coerce a particular decision.

RCAR holds in high respect the value of potential life; we do not take the question of abortion lightly, and we are NOT PRO-ABORTION. WE ARE PRO-CHOICE, and WE ARE PRO-LIFE. While we do not support abortion a positive alternative to responsible use of contraception, nor for purposes of sex selection, we know of no instances where this has occurred. We also believe that all women should be supported in their decision to carry their pregnancy to term, and our member groups aggressively support programs such as the Special Supplemental Food Program for Women, Infants and Children (WIC), Aid to Families with Dependent Children (AFDC), child care, food stamps, etc., that can help them do so.

RCAR strongly supports federally funded family planning programs, which provide primary contraceptive and gynecologic care for about 4.1 million women who might not otherwise be able to obtain services. These programs, most of which are funded by Title X of the Public Health Services Act, play a critical role in promoting maternal and child health. While these programs do not provide abortions, they do reduce the need for abortions by reducing unintended pregnancy. A mere 8% of women at risk of unintended pregnancy used no form of contraceptives, but accounted for more than 57% of actual unintended pregnancies.

Since 1985, funding for Title X has actually decreased by over $27 million. As a result of inflation, restoration of services would require funding at a level of approximately $230 million for FY91. S.110, the reauthorization of Title X programs as passed by the Senate Labor and Human Resources Committee, would authorize $171 million. We urge this subcommittee to provide for full funding of the amount authorized by S.110.

Furthermore, we firmly believe that abortion should remain a safe, legal and accessible option to all women, regardless of their economic status. A woman with a problem pregnancy is facing a complex decision, rather than a simple question of right or wrong. In reaching a decision she must weigh all options in light of the teachings of her religion, her medical, social and economic situation.

The so-called Hyde Amendment to the Labor, Health and Human Services and Education Appropriations bill restricts the use of Medicaid funds for abortions except in the most extreme case when it is necessary to save a woman's life. Abortions cannot be provided for women who are rape or incest victims, for women whose health is seriously jeopardized by pregnancy, or for women who carry abnormal fetuses. Poverty increases the risk of nutritional deficiencies, limited access to health care, and illness that may be exacerbated by pregnancy, such as diabetes, heart disease, hypertension and cancer. Thus the Hyde amendment hurts Medicaid recipients by coercing a particular decision that may be detrimental to health.

For the nine percent of women of reproductive age who rely on Medicaid for health care, the only alternative to carrying a crisis pregnancy to term is to finance an abortion personally. The average fee for an early abortion, although only one tenth the cost of prenatal care and delivery which is covered by

Medicaid, is more than half the monthly income of a family on AFDC. While a majority of Medicaid eligible women who need abortions do eventually obtain them, it is only at great sacrifice to themselves and their families.

The difficulty in raising money to pay for it can often lead to delay in obtaining an abortion, which significantly increases the risks to the woman. While abortion is considered to be one of the safest medical procedures when performed by a licensed practitioner, each week of delay heightens the possibility of serious health complications by 20%. In 1982, women who were eligible for Medicaid obtained abortions two to three weeks later than other women. Ironically, the cost of an abortion also increases with the delay.

RCAR is especially concerned that the Hyde amendment disproportionately affects women of color. Approximately 18.8% of blacks, compared with only 4% of whites, rely on public-assistance for their health care. This statistic represents a tremendous indictment for the racism and injustice in our society. These are only exacerbated when recipients of public assistance are denied medically necessary health care options that are guaranteed to the general population as a fundamental right.

THEREFORE, RCAR RESPECTFULLY REQUESTS THAT THE SENATE LABOR, HEALTH AND HUMAN SERVICES APPROPRIATIONS SUBCOMMITTEE ELIMINATE RESTRICTIONS ON THE USE OF MEDICAID FUNDS FOR ABORTIONS, AND RAISE THE LEVEL OF FUNDING OF TITLE X FAMILY PLANNING PROGRAMS TO $171 MILLION.

# STATEMENT OF THE NATIONAL ASSOCIATION OF REHABILITATION FACILITIES

Thank you Chairman Harkin and the other members of the subcommittee for allowing the National Association of Rehabilitation Facilities to submit written testimony regarding fiscal year 1991 funding for the Departments of Labor, Health and Human Services, Education and Related Agencies.

NARF is a national leader in the area of rehabilitation representing over 700 community-based vocational, medical, and residential rehabilitation facilities. Our testimony will cover numerous programs which are aimed at assisting persons with disabilities. The areas that we will address are covered under the Rehabilitation Act, the Health Omnibus Programs and Extension Act of 1988, Title XX, and the Job Training Partnership Act.

Perhaps no other time in recent history has the need been greater to expand programs that assist persons with disabilities. The entire disability community anxiously awaits the passage of the Americans With Disabilities Act, which will put persons with disabilities on an equal footing with the rest of the American population. However, this legislation, Chairman Harkin, which you so deftly moved through the Senate, has no funding mechanism. Therefore, many of the programs that are currently in existence remain the only vehicle that can carry out the spirit of the ADA legislation. The National Association of Rehabilitation Facilities stands ready to utilize those programs in order to implement this landmark civil rights legislation. Our members view themselves as civil rights leaders within their communities who will make the ADA legislation, when it passes, a living civil rights document.

## REHABILITATION ACT

The Rehabilitation Act of 1973 remains the foundation for vocational services for persons with disabilities and the key link between the spirit of ADA and the reality of moving persons with disabilities into an integrated America.

The Administration has requested that the Vocational Rehabilitation State Grants Program be funded at $1.615 billion for FY 1991. This represents a meager increase of 4.5%, which barely allows this program to keep pace with inflation. NARF recommends that the subcommittee fund the State Grants Program at the level authorized, $1.875 billion. Additional funding for this program will allow states to maintain and enhance their level of services, while providing a jump start for the ADA legislation when it is enacted.

Another key component of the Rehabilitation Act is the Supported Employment Program. This program offers persons with disabilities an opportunity to participate in competitive work in integrated, community-based settings. In addition, the program provides the necessary on-going support for individuals with disabilities to assist them in performing their jobs. Approximately, three-fourths of supported employment service providers are traditional rehabilitation programs offering rehabilitation services. Yet, we have heard that sparse funding for this program means that services to consumers cannot be as extensive as they should be because of lack of funding. Therefore, we encourage the subcommittee to increase funding for this program to $30.949 million, the fully authorized appropriation.

Also authorized under the Act, and of great importance to individuals with disabilities, rehabilitation facilities, community organizations, labor unions, and businesses is the Projects With Industry Program (PWI). This program fosters public/private partnerships through business advisory councils. Most PWIs already provide the type of assistance and advice that the business community will need to comply with ADA. The training is designed specifically for jobs available in the business community. The PWI program provides a natural link between the intent of the ADA and the reality of it being carried out. Job training, placement, support services, job modification, special aids, appliances or adaptive equipment, and the modification of facilities or equipment are all services that can be provided under PWI. For fiscal year 1991, the President's budget called for level funding for the PWI program, $18.76 million. This program's authorized appropriation is $19.925 million. The President's request is $1.16 million below that amount. NARF recommends the full level of funding as authorized by the Act for the following reasons:

- PWI returns $3.42 for each Federal dollar spent;
- Over $4 million in savings and payments would be realized for the additional $1.16 million appropriated;
- An additional 996 persons with disabilities will be trained and given jobs in the competitive labor market;
- An additional $10,579,512 will be earned by these PWI graduates in the first year;
- An additional $879,468 in federal income tax will be paid in the first year of employment; and
- An additional 109 SSI and SSDI recipients will be employed.

With regards to training, rehabilitation facilities, both medical and vocational, continue to face severe shortages in personnel and training programs that provide in-service and retraining for existing staff. The strength and effectiveness of rehabilitation facilities is dependent upon an adequate supply of appropriately trained and competent practitioners. It is estimated that rehabilitation facilities will need to attract between 100,000 and 300,000 new staff by the year 1991. These new employees will require proper training. Yet, funding for training programs under Section 304 of the Act has remained static over the past few years. NARF recommends the full level of funding of $38.5 million for FY 1991.

## HEALTH OMNIBUS PROGRAMS AND EXTENSION ACT

Another source of needed training funds is the Health Omnibus Programs and Extension Act of 1988. The 100th Congress enacted the Health Omnibus Programs and Extension Act which contains two provisions that would make available in 1991 $2 million for faculty and program strengthening, and for traineeships for advance training of allied health professionals, including rehabilitation therapists. The funding levels are grossly inadequate for the present rehabilitation needs of our nation's elderly and persons with disabilities. Given the extreme shortages of occupational and physical therapists, speech language pathologists, and audiologists, NARF recommends that the subcommittee appropriate the full authorization level under the Act of $4 million for FY 1991.

## TITLE XX

The Title XX Social Services Block Grant is as major source of funding for non-institutional community-based services that serve individuals with disabilities. In many states, this program provides the funding that allows individuals to remain self-supporting. Title XX received a small increase 0 of $62 million for FY 1990. The President has requested an additional $38 million for this program totalling $2.8 billion. Congress has allowed this program to be funded at a higher level. NARF recommends that Title XX be given a substantial increase in funding for the expansion of services currently being provided, such as referral and counseling, training and related services, and an appropriate combination of services designed to meet the special needs of children, the aged, the mentally retarded, the blind, the emotionally disturbed, the physically handicapped, and alcoholic and drug addicts.

## JOB TRAINING PARTNERSHIP ACT

The Job Training Partnership Act (JTPA) provides job training services to individuals with disabilities through Title IIA and the seven national projects funded under Title IV (Pilot and Demonstrations Account). Rehabilitation facilities have played a key role in seeing that persons with disabilities, as well as non-disabled individuals, receive training through the JTPA program. The seven projects under Title IV operate nationwide in 65 sites and placed over 9,000 individuals in jobs in FY 1987. Since funding for the JTPA program has been reduced over the last two years, NARF recommends that Title IIA as well as the Pilot and Demonstrations Program be returned to at least the 1988 appropriations level of $1.809 billion and $39 million respectively.

Mr. Chairman, the National Association of Rehabilitation Facilities appreciates this opportunity to share our views on these important issues and we hope that you will strongly consider our recommendations.

# STATEMENT OF THE NATIONAL CENTER FOR HEALTH EDUCATION

The National Center for the Health Education (NCHE) is pleased to present written testimony. NCHE was created in 1975 at the recommendation of the President's Committee on Health Education. Since then, the Center has worked to improve the health of the American people through health education. Specifically, during the last several years the Center has focused on the goal of implementing comprehensive school health education in every American school by the year 2000.

## School Health Promotion

Recent research has shown that schools can offer appropriate and systematic means of preparing young people to avoid health risks. A major study of four school health curricula, including Growing Healthy, a comprehensive school health education program managed by NCHE, demonstrated that students who were instructed from these curricula scored substantially better on measures of health knowledge and attitudes than students in a control group. Seventh graders were three times more unlikely to start smoking than control-group students (Journal of School Health, October, 1985).

## Today's Schools

More than 47 million students are enrolled in kindergarten through grade 12 in almost 16,000 public school districts. Despite broad recognition of the opportunity for health improvement through schools, the Centers for Disease Control (CDC) estimates that as few as five percent of schools offer a planned, sequential, comprehensive school health education curriculum in kindergarten through grade 12 that addresses the physical, mental, emotional and social dimensions of health. Even fewer schools have a comprehensive school health program that also addresses school health services, school health environment, physical education, school counseling, school food services and integrated school, family and community health promotion efforts, all of which are necessary components of an effective school health program.

Today's students face an array of complex health problems. Nearly 70% of all deaths among those age 1-24 is due to only four, preventable, causes--motor vehicle accidents(33%), other unintentional injuries (15%), homicide (10%), and suicide(10%) (National Center for Health Statistics, Monthly Vital Statistics Report, Vol. 36, no. 13, July 29, 1988, pp 18-19). In addition, while not necessarily reflected in mortality statistics, the young people of our Nation suffer increasingly from adverse effects of drug and alcohol abuse. Comprehensive school health education programs provide students with information and decision-making skills that change the way they act. They learn to avoid drugs, for example, within a broader context: finding out how their body systems work, improving their self-esteem, and learning to value good health.

## Federal Funding Assists in the Dissemination of Comprehensive School Health Education Programs

Department of Education (DOE)

The Augustus F. Hawkins-Robert T. Stafford Elementary and Secondary School Improvement Amendments of 1988 authorized the establishment of the Office of Comprehensive School Health Education (CSHE) within the Office of the Secretary. Under the 1989 grant competition, 80 applications representing 35 states were received, requesting a total of $19,339,367. Last year, with limited funding, only eighteen projects were funded. Collectively, these projects and information centers will provide educators at the State and local levels with a resource base from which to draw when developing and strengthening school health education programs. One of these funded programs is through the South Dakota (S.D.) Department of Health. Most of South Dakota's public and private schools serve a large number of Native American students and do not have the resources necessary for implementation of comprehensive health education programs. With DOE funds the project will support implementation of a comprehensive school health program in four targeted S.D. counties. In addition, supplemental teaching materials specific to Sioux Indian culture will be developed for use in the curricula. Because of programs of this caliber, the Center supports the growth of the Office of CSHE and recommends increasing funding from $4 to $6 million in fiscal year 1991.

Department of Health and Human Services/Centers for Disease Control (CDC). Currently, all funding in the area of school health education within CDC is in the area of AIDS education. The President's Commission on HIV infections identified comprehensive school health education as the most effective solution in the fight against AIDS and substance abuse. During this past year through cooperative agreements with 20 national organizations and with 55 State and 16 local departments of education, CDC's Division of Adolescent and School Health provided assistance to State and local education agencies to improve the health of children and adolescents by reducing their health risks related to injuries, HIV infection, cardiovascular diseases, cancer, drug abuse, and other health problems. These agreements stress that comprehensive school health education is needed to help school-aged youth make responsible decisions about their behaviors and lifestyles. In addition, thirty regional training centers will train school and community personnel to use comprehensive health education curricula. This is an excellent start. CDC plans to expand these efforts during 1991. NCHE requests that Members of this Subcommittee support these school-based activities and encourage CDC's Center for Chronic Disease Prevention and Health Promotion to expand and integrate comprehensive school health education programs within all of its divisions and offices.

Summary

The National Center for Health Education is pleased with the renewed National and State focus on schools and the pursuit of excellence in educating our children. The Center believes the schools are an important setting for health education and health programs and is eager to work with public efforts to implement comprehensive school health programs in all of our schools by the year 2000--with special emphasis on reaching cities with large numbers of youth at high risk of disease and injury. Thank you for this opportunity to present our comments.

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## STATEMENT OF SENATOR SPARK MATSUNAGA

Thank you very much, Mr. Chairman. As Chairman of the Senate Labor and Human Resources Subcommittee on Aging, which has legislative jurisdiction over the Older Americans Act, I greatly appreciate having this opportunity to testify in support of Fiscal Year 1991 appropriations for the Act.

The Older Americans Act was enacted in the mid-1960's along with the expansion of the Social Security and Food Stamp programs, and the new Medicare and Medicaid Acts as part of a government-wide effort to address the needs of senior citizens in the United States, particularly low-income and middle-income senior citizens. One of the distinctive features of the Older Americans Act was that it sought to address not just the physical and income needs of older Americans, but was also intended to assure a dignified old age for all Americans. For example, Congress found in 1965 that many elderly Americans lived isolated and lonely lives and sought to remedy this through a congregate meals program and by providing better transportation services for senior citizens. Through its nutrition programs -- congregate meals and meals-on-wheels -- the Older Americans Act has also enabled elderly Americans to lead healthier and more vigorous lives.

The Older Americans Act has been amended several times since 1965, most recently in 1987 and, today, it is without doubt one of the federal government's most successful and popular programs, enjoying a very high level of public support. I am, therefore, deeply concerned that the Administration's FY-91 budget proposes to reduce or freeze funding for these programs. I call to your attention the report on the unmet needs of the elderly, which was required by the 1987 amendments to the Older Americans Act and which shows that despite the gains made in the last 25 years, there remains an unfulfilled need for services to the elderly -- especially the poor elderly.

Moreover, with the aging of the baby boomers and with the number of elderly Americans expected to increase by at least one-third by the early to mid-21st Century, this is certainly no time to reduce funding for services provided under the Older Americans Act.

Yet, the Administration would effectively reduce services to the elderly if its Fiscal Year 1991 budget is adopted without change. For example, services under Title III of the Older Americans Act, which includes among other things nutrition services, transportation, and grants for in-home services for the frail elderly, were frozen at $710 million -- the same amount provided in FY-90. No allowance was made for needed expansion of these services, or for inflation. Services under Title VI of the Older Americans Act, which provides a variety of services to Native American elderly who are among the neediest in the nation, were also frozen at the FY-90 level, and the Administration proposes to cut funding for Title V of the Older Americans Act, also known as the Senior Community Service Employment Program (SCSEP). SCSEP, which is administered by the U. S. Department of Labor, provides job training for low-income senior citizens who work on local community service projects. Paid the minimum wage, participants in the program are usually able to move on to unsubsidized jobs in the private sector. Since Congress increased the minimum wage last year, an increase in funding for this program would be needed in any event, just to maintain the current number of participants. However, the Administration proposes to reduce funding for SCSEP by $14.2 million, a reduction which will mean the loss of more than 6,000 SCSEP jobs.

Mr. Chairman, it is clear that the Administration's budget proposals would impact most heavily on the neediest of our senior citizens. I am, therefore, requesting that this Subcommittee restore the cuts in Title V of the Older Americans Act and provide an increase in funding to compensate for the increase in the minimum wage. I further request that full funding of $22 million be provided for Title VI of the Older Americans Act -- an amount which will make it possible to meet the nutrition and transportation needs of American Indians, Alaskan Natives, and Native Hawaiians who often live in rural poverty and isolation. Finally, I request at least a modest increase of 4 to 5 percent be provided for Title III of the Older Americans Act so that the majority of OAA services can keep pace with inflation.

I ask for the Subcommittee's full and favorable consideration of this request. On behalf of our Nation's older Americans, thank you very much.

# STATEMENT OF THE FEDERAL PROFESSIONAL NURSES ASSOCIATION

Mr. Chairman:

Despite the best efforts of this Committee, the quality of government employee health care continues to deteriorate and the job security of the full-time Federal nurses who staff the PHS Units is in more serious jeopardy today than when we last reported to you.

The Committee has adopted Report language advising the Public Health Service that its proposal to reassign full-time Federal nurses as resource nurses contravenes the Committee's express direction that government health units be staffed with full-time Federal occupational health professional positions. The Committee also directed PHS to submit a report explaining the impact of the proposal on the quality of health care provided Federal employees and its effect on the rights of the full-time nursing staff. The Department has not complied with the Committee's directions and has yet to file the report that you requested.

The Union has tried repeatedly, but without success, to get the Department to acknowledge and respect the directions of this Committee. Finally, faced with the threat of imminent implementation of the Resource Nurse Proposal, the Union filed an unfair labor practice charge against the Department. The matter is now pending before the Federal Service Impasses Panel of the Federal Labor Relations Authority. Throughout the course of the proceedings, the Department has remained inflexible in its position that it intends to reassign full-time nurses from the Units where they serve and to replace them with contracts. To this day, the Department adamantly and arrogantly refuses to obey the directions of this Committee to desist from implementing the proposed transfers.

The Department action, we believe, places the health of government workers at risk. While the demand for the specialized services of occupational health nurses continues to grow, the Department insists on replacing full-time Federal nurses with private contract nurses. The use of contract nurses to staff Public Health Units is the reason for the deterioration in the quality of health care government workers receive in the workplace.

Most contract nurses are temporary employees. They do not stay long at any one agency. They do not get to know the employees and their environment. Consequently, there is no continuity in patient care. Contract nurses receive little or no supervision. Furthermore, the Department has yet to institute a screening process to insure that contract nurses are qualified in occupational health nursing. These qualifications -- according to the American Association of Occupational Health Nurses -- are derived from several disciplines in the health sciences, including nursing, medicine, safety, industrial hygiene, toxicology, administration, and public health epidemiology.

PHS officials admit privately that privatization of public health services cannot be justified either on the basis of efficient public health practices or by the claim of potential cost savings. Nevertheless, the Department continues to foister privatization on government employees with the promise that savings will be realized by contracting out nursing services under OMB Circular A-76.

These "savings" are bogus; they have never materialized. In fact, the General Accounting Office testified recently that there is no proof that privatization saves money or promotes efficiency.

As you know, Mr. Chairman, the resources of our small Union are very limited. We nurses are no match in size or strength for the Department of Health and Human Services, which thus far has shown neither compassion for our position nor respect for your authority. We are compelled, therefore, to request your assistance once again, for ourselves and for the government employees we serve.

We urge this Committee to include language in your Report prohibiting the reassignment of full-time Federal nurses from the PHS Units where they serve in the Washington, D.C. area in order to replace them with contract personnel. We also request that the Committee adopt language disagreeing with any proposed reduction in full-time nursing positions for fiscal year 1991 to comply with OMB Circular A-76 management initiatives.

We request further that you direct the Department to submit a report to the Committee which shall include an assessment of the impact of contracting out nursing services on the quality of health services provided to government workers at the worksite, as well as a comparison of the estimated versus actual savings for A-76 studies performed over the past five years.

Finally, Mr. Chairman, we nurses want you to know how deeply we appreciate the Committee's efforts to preserve the quality of health care for Federal employees, and we are thankful as well for the concern you have shown for our welfare.

## Proposed Appropriations Committee Report Language

Federal employees occupational health

> The Committee believes the Public Health Service proposal to reassign Division of Federal Employee Occupational Health Nurses in the Washington, D.C. area, and to designate these nurses as resource nurses, contravenes the express direction of this Committee that Government health units be staffed with full-time Federal occupational health professional positions. Therefore, the Committee directs that the Public Health Service suspend implementation of these reassignments pending study of the advisability of contracting out nursing services.
>
> Moreover, the budget submitted by the Department of Health and Human Services has requested reductions to reflect savings anticipated as a result of contracting out certain activities to private industry pursuant to OMB Circular A-76. The Committee is concerned that these proposed "savings" may never materialize. Furthermore, the Committee has serious doubts regarding the propriety of privatizing the provision of occupational health nursing services.

For these reasons, the Committee does not agree to the requested reductions for A-76 management initiatives. Within the available budget authority provided the various agencies of the Department of Health and Human Services, those positions which were proposed for reduction shall remain available for full-time Federal nursing personnel.

The Department is directed to submit a report within 90 days on the impact to date of contracting out on the quality of health care provided Federal employees. This report should also contain a comparison of the estimated versus actual savings for A-76 studies performed over the past five years.

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# STATEMENT OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS

CHAIRMAN, ON BEHALF OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS AND THE 21,000 PAs WE REPRESENT, I APPRECIATE THIS OPPORTUNITY TO PRESENT OUR VIEWS ON THE FY 1991 LABOR, HEALTH AND HUMAN SERVICES APPROPRIATIONS BILL.

THE ACADEMY APPRECIATES THE SUPPORT THE SENATE APPROPRIATIONS COMMITTEE IN GENERAL, AND THIS SUBCOMMITTEE IN PARTICULAR, HAS SHOWN FOR PA EDUCATION OVER THE YEARS. LAST YEAR BOTH SENATE AND HOUSE APPROPRIATIONS COMMITTEES RECOMMENDED SIGNIFICANT INCREASES IN FEDERAL SUPPORT FOR PA EDUCATION. AS YOU KNOW, THE ACADEMY SUPPORTED THE SENATE'S RECOMMENDATION OF $5.1 MILLION RATHER THAN THE HOUSE RECOMMENDATION OF $4.65 MILLION. ULTIMATELY, THE FINAL APPROPRIATION REPRESENTED A COMPROMISE BETWEEN THE TWO FIGURES - $4.875 MILLION.

AS A RESULT OF THAT INCREASE, I AM PLEASED TO REPORT THAT THE DEPARTMENT WAS ABLE TO FUND ALL OF THE COMMITMENTS IT HAD MADE DURING THE FY 1989 FUNDING CYCLE (PA GRANTS ARE MULTI-YEAR), AND STILL HOLD A COMPETITIVE GRANT CYCLE FOR NEW PROPOSALS. THIS YEAR, ONE NEW PA PROGRAM WAS ABLE TO RECEIVE A GRANT WITHOUT ADVERSELY AFFECTING EXISTING GRANTEES. THIS PROGRAM, LOCATED IN CALIFORNIA, WILL ADD NEW PAs TO THE WORK FORCE IN A FEW YEARS.

IT IS ALSO WORTH NOTING, MR. CHAIRMAN, THAT BOTH THE AIR FORCE AND NAVY HAVE RESTARTED THEIR PA PROGRAMS THIS YEAR. ONCE ACCREDITED, THIS WILL MEAN FOUR NEW PROGRAMS (ANOTHER NEW PROGRAM RECEIVED MONEY FROM THE FY 1989 APPROPRIATION) ON LINE AND PRODUCING GRADUATES. ALL OF THIS INTEREST IS BEING DRIVEN BY THE SAME FACTOR - A SEVERE SHORTAGE OF PHYSICIAN ASSISTANTS.

IN ADDITION TO THESE FOUR NEW PROGRAMS, THE COMMITTEE SHOULD BE AWARE THAT THERE ARE A NUMBER OF STATES SERIOUSLY CONSIDERING STARTING PA PROGRAMS BECAUSE OF THE ACUTE PA SHORTAGE IN THEIR STATES. THESE ARE: NEVADA, OREGON, MINNESOTA, MAINE, NEW YORK, AND TEXAS.

NEVADA, OREGON, MINNESOTA AND MAINE, ARE PARTICULARLY IMPORTANT BECAUSE THERE ARE PRESENTLY NO PROGRAMS LOCATED IN THESE STATES. NEW YORK, DESPITE HAVING SEVEN ACCREDITED PA PROGRAMS AND AN EIGHTH IN THE PROCESS, IS LOOKING INTO THE POSSIBILITY OF STARTING ADDITIONAL PROGRAMS!

IN ADDITION TO STARTING NEW PROGRAMS, EXISTING PA PROGRAMS ARE LOOKING INTO THE POTENTIAL TO EXPAND CURRENT CLASS SIZES WITHOUT DIMINISHING THE QUALITY OF THE EDUCATION. EFFORTS TO INCREASE THE APPLICANT POOL ARE BEGINNING TO PAY OFF AND IT APPEARS THAT WE WILL SEE AN

INCREASE IN THE NUMBER OF QUALIFIED APPLICANTS IN 1990 OVER 1989.

AT A TIME WHEN SO MANY OTHER HEALTH PROFESSIONS ARE SEEING PROGRAMS CLOSE DUE TO A DROP IN APPLICANTS, THE PA PROFESSION ANTICIPATES A GROWTH OF GREATER THAN 10% IN THE NUMBER OF ACCREDITED PROGRAMS OVER THE NEXT FEW YEARS.

ALTHOUGH THIS IS GOOD NEWS, MR. CHAIRMAN, IT ALSO MEANS THAT THERE WILL BE AN INCREASED DEMAND FOR FEDERAL ASSISTANCE TO HELP GET THESE PROGRAMS STARTED AND RUNNING SMOOTHLY. THIS NEW MONEY WILL BE NEEDED, NOT TO PROVIDE THE TOTAL SUPPORT BUT RATHER TO BE USED WITH STATE AND/OR PRIVATE (INSTITUTIONAL) MONEY TO HELP GET THEM STARTED.

AS YOU CAN IMAGINE, STARTING A PROGRAM IS AN EXPENSIVE PROPOSITION, PARTICULARLY BECAUSE IN THE EARLY STAGES THERE IS NO REVENUE COMING IN. A COMBINATION OF FEDERAL/STATE AND INSTITUTIONAL SUPPORT IS CRITICAL TO THE OVERALL SUCCESS OF A NEW PROGRAM.

DESPITE THIS GOOD NEWS, CONCERN HAS BEEN EXPRESSED, BOTH AT THE FEDERAL LEVEL AND WITHIN THE HEALTH POLICY COMMUNITY, THAT PERHAPS PAs ARE TURNING AWAY FROM THEIR TRADITIONAL AREAS OF MEDICINE - PRIMARY CARE, IN FAVOR OF MEDICAL SPECIALTIES. THE QUESTION HAS BEEN ASKED, IF THIS IS THE CASE, SHOULD THE FEDERAL GOVERNMENT CONTINUE TO SUPPORT PA EDUCATION?

CLEARLY THE PERCENTAGE OF PAs IN PRIMARY CARE MEDICINE IS DOWN BY HISTORICAL STANDARDS; HOWEVER, WHEN COMPARED TO ANY OTHER MEDICAL PROFESSION, THE NUMBERS ARE FAR HIGHER. IN ADDITION, THERE ARE MORE PAs WORKING IN RURAL COMMUNITIES, AS A PERCENTAGE OF THE PROFESSION, THAN ANY OTHER HEALTH PROFESSION. TO THE QUESTION - SHOULD THE FEDERAL GOVERNMENT CONTINUE TO SUPPORT PA EDUCATION WE ANSWER A RESOUNDING YES!

CERTAINLY MARKET FORCES ARE CREATING OPPORTUNITIES FOR PAs THAT DID NOT EXIST A FEW YEARS AGO. THE PROFESSION CANNOT STOP THIS EXPANSION. BUT FEDERAL AND STATE HEALTH POLICY MAKERS MUST ALSO UNDERSTAND THAT A SIGNIFICANT REASON FOR THE CHANGE IN PA PRACTICE SEEN OVER THE PAST FEW YEARS HAS BEEN THE DIRECT RESULT OF CHANGES IN GOVERNMENT POLICY.

IN OUR VIEW THERE ARE TWO EXPLANATIONS FOR THE CHANGE IN PA DEMOGRAPHICS.

1. CHANGES IN GRADUATE MEDICAL EDUCATION AT BOTH THE FEDERAL AND STATE LEVEL;
2. SERIOUS ERRORS MADE BY GMENAC IN ITS 1980 REPORT.

## GRADUATE MEDICAL EDUCATION

CHANGES AT BOTH THE FEDERAL AND STATE LEVEL IN GRADUATE MEDICAL EDUCATION FINANCING AND WORK-HOURS HAVE HAD A PROFOUND IMPACT ON THE PA PROFESSION.

AS THE FEDERAL GOVERNMENT REDUCED SUPPORT FOR GRADUATE MEDICAL EDUCATION THROUGH THE MEDICARE PROGRAM, HOSPITALS, PARTICULARLY INNER CITY HOSPITALS, FOUND IT NECESSARY TO EITHER DECREASE OR ELIMINATE THEIR RESIDENCY TRAINING PROGRAMS. THIS LOSS OF PHYSICIAN MANPOWER, AT A TIME WHEN PATIENT POPULATIONS WERE RAPIDLY INCREASING, FORCED HOSPITALS TO SEEK ALTERNATIVES TO RESIDENTS AS HOSPITAL HOUSE STAFF. THE LOGICAL CHOICE BECAME PHYSICIAN ASSISTANTS.

THE NUMBER OF PAs PRESENTLY WORKING AS HOSPITAL HOUSE STAFF, IN POSITIONS PREVIOUSLY FILLED BY RESIDENTS, IS REAL AND GROWING. WE EXPECT THIS TREND TO CONTINUE FOR THE FORESEEABLE FUTURE.

THE RESIDENT SITUATION WAS COMPOUNDED FURTHER WHEN STATES, SUCH AS NEW YORK, BEGAN RESTRICTING THE NUMBER OF HOURS RESIDENTS COULD WORK. THIS AGAIN CAUSED A MANPOWER CRISIS WHICH FURTHER INCREASED DEMAND FOR PAs IN THE HOSPITAL ARENA. ACCORDING TO THE HEALTH AND HOSPITALS CORPORATION OF NEW YORK, NEW YORK HOSPITALS ALONE COULD HIRE EVERY PA STUDENT GRADUATING FROM NEW YORK PROGRAMS (OF WHICH THERE ARE SEVEN) AND STILL NOT HAVE ENOUGH PAs TO FILL ALL OF THE ANTICIPATED POSITIONS.

### Graduate Medical Education National Advisory Committee (GMENAC)

AS YOU KNOW, MR. CHAIRMAN, OVER THE PAST FEW YEARS, MANY HAVE BEGUN QUESTIONING THE FINDINGS OF THE 1980 GMENAC REPORT. INTERESTINGLY, WE COME HERE TODAY, NOT TO BURY GMENAC, BUT TO PRAISE IT. YOU SEE, MR. CHAIRMAN, GMENAC PREDICTED THE VERY SHORTAGE WE ARE PRESENTLY EXPERIENCING.

IN ASSESSING THE PA MANPOWER SITUATION, THE ACADEMY DECIDED TO GO BACK AND REEXAMINE THE GMENAC REPORT AND FIND OUT WHERE IT WENT WRONG. TO OUR SURPRISE, MR. CHAIRMAN, WE FOUND THAT THE RESEARCH WAS NOT WRONG, AND IN FACT IT WAS RIGHT ON TARGET. UNFORTUNATELY, THE WAY GMENAC CHOSE TO REPORT ITS FINDINGS OBSCURED THE FACT THAT IT PREDICTED A MID-LEVEL HEALTH CARE PROVIDER SHORTAGE BY 1990!

AS YOU KNOW, THE GMENAC REPORT USED THE RATHER REVOLUTIONARY IDEA OF A NEEDS BASED MODEL FOR PROJECTING FUTURE HEALTH MANPOWER DEMAND. AFTER DETERMINING THE PROJECTED NEED, THE PANELS THEN LOOKED AT PROJECTED SUPPLY OF HEALTH PROVIDERS TO MEET THAT NEED AND THEN PREDICTED POSSIBLE OVER-SUPPLY OR UNDER-SUPPLY OF HEALTH CARE PROVIDERS.

IN DEVELOPING ITS MODELS FOR HEALTH DEMAND IN 1990, GMENAC ASSUMED THAT MANY OF THE VISITS NORMALLY PERFORMED BY PHYSICIANS WOULD BE DELEGATED TO NON-PHYSICIAN PROVIDERS SUCH AS PAs, NURSE PRACTITIONERS AND, IN THE CASE OF OB/GYN CARE, NURSE MIDWIVES.

FOR EXAMPLE, THE DELPHI PANEL ESTIMATED THAT IN 1990 THERE WOULD BE APPROXIMATELY 1.7 BILLION ADULT VISITS. OF THESE FULLY 22% OR 390 MILLION COULD REASONABLY BE EXPECTED TO BE DELEGATED TO NON-PHYSICIANS (PA, NPs AND CNMs).

A SEPARATE PANEL WAS LOOKING AT THE ANTICIPATED SUPPLY OF PAs, NPs AND CNMs. THIS PANEL PROJECTED A SUPPLY OF APPROXIMATELY 20,000 PAs, 20,000 NPs AND 5,000 CNMs IN 1990.

IT BECAME QUITE APPARENT THAT 45,000 NON-PHYSICIANS WAS INSUFFICIENT TO HANDLE 22% OF ALL ADULT VISITS. BUT RATHER THAN REPORT THIS AS A SERIOUS SHORTAGE OF PAs, NPs and CNMs, THE GMENAC SIMPLY DECIDED TO ASSUME THAT THESE VISITS WOULD NOT BE DELEGATED. THUS, INSTEAD OF 22% OF ALL ADULT VISITS BEING DELEGATED, AS ORIGINALLY ANTICIPATED, GMENAC REPORTED THAT ONLY 12% OF ALL VISITS WOULD BE DELEGATED, THUS LEAVING YOU WITH A SUPPLY-DEMAND RATIO IN RELATIVE EQUILIBRIUM.

THE AMAZING FACT IS THAT THE DELPHI PANELS WERE RIGHT. THE ANTICIPATED MANPOWER PROJECTIONS ARE RELATIVELY CLOSE TO WHAT WE HAVE IN 1990 AND BASED UPON DEMAND FOR NON-PHYSICIANS, WE KNOW THAT PHYSICIANS ARE SEEKING TO DELEGATE CARE TO PAs IN A MANNER CONSISTENT WITH THE INITIAL DELPHI PROJECTIONS.

THIS "DOCTORING" OF THE NUMBERS WAS, TO SAY THE LEAST, UNFORTUNATE FOR MILLIONS OF AMERICANS WHO DO NOT HAVE ACCESS TO HEALTH CARE BECAUSE OF AN INADEQUATE SUPPLY OF HEALTH CARE PROVIDERS.

THIS STATISTICAL SLIGHT OF HAND BY GMENAC HAS HAD A DISASTROUS IMPACT ON RURAL AMERICA WHERE CHRONIC SHORTAGES OF QUALIFIED HEALTH PROVIDERS CONTINUE DESPITE THE ROSY PROJECTIONS OF GMENAC.

## CONCLUSION

THE PA PROFESSION IS COMMITTED TO ENSURING ACCESS TO HEALTH CARE FOR ALL AMERICANS. THE PROFESSION HAS REDOUBLED ITS EFFORTS TO FOCUS ATTENTION ON PRIMARY CARE MEDICINE AND UNDERSERVED POPULATIONS. DESPITE INCREASING PRESSURE FOR SPECIALIZATION, PROGRAMS HAVE INTENSIFIED THEIR EFFORTS TO RECRUIT INDIVIDUALS INTO THE PROFESSION WHO HAVE AN INTEREST IN PRIMARY CARE MEDICINE - PARTICULARLY AS IT RELATES TO UNDERSERVED POPULATIONS.

AS YOU MAY KNOW, WE ARE PRESENTLY WORKING WITH THE FEDERAL OFFICE OF MIGRANT HEALTH AND THE NATIONAL RURAL HEALTH ASSOCIATION ON THE ESTABLISHMENT OF THE FIRST POST-GRADUATE FELLOWSHIP IN MIGRANT HEALTH. WE BELIEVE THIS PROJECT, IF SUCCESSFUL, CAN SERVE AS A MODEL FOR OTHER HEALTH PROFESSIONS - PARTICULARLY PHYSICIANS AND NURSES.

AS I MENTIONED, WE ARE WORKING WITH STATES AND PA CHAPTERS TRYING TO START NEW PROGRAMS IN AREAS OF THE COUNTRY WHERE NONE PRESENTLY EXISTS.

BUT AS I MENTIONED, MR. CHAIRMAN, WE NEED YOUR HELP. STARTING A PROGRAM IS NOT EASY AND THE COSTS CAN BE HIGH.

THIS YEAR, PA PROGRAMS ARE AUTHORIZED TO RECEIVE $5.4 MILLION DOLLARS. WE URGENTLY REQUEST THAT THIS SUBCOMMITTEE APPROPRIATE THE FULL $5.4 MILLION. WE REALIZE THIS IS SIGNIFICANT AND NOT EASY IN TIMES WHEN BUDGET DOLLARS ARE TIGHT. BUT ALSO REALIZE, MR. CHAIRMAN, THAT WE HAVE LOST ALMOST 10 YEARS WORTH OF HEALTH PROFESSIONS ASSISTANCE FROM THE FEDERAL GOVERNMENT BASED UPON FALSE AND MISLEADING DATA. IF WE ARE GOING TO TURN THE TIDE, WE MUST DO SO NOW!

YOUR PAST SUPPORT FOR ADEQUATE FUNDING FOR PA EDUCATION HAS BEEN GREATLY APPRECIATED, MR. CHAIRMAN. WE HOPE WE CAN CONTINUE TO COUNT ON YOUR SUPPORT IN THE YEARS TO COME. THE ACADEMY IS ALWAYS AVAILABLE TO ANSWER ANY QUESTIONS YOU MIGHT HAVE.

## STATEMENT OF THE CHILD WELFARE LEAGUE OF AMERICA, INC.

On behalf of the Child Welfare League of America, thank you for the invitation to submit testimony regarding our views on FY 1991 appropriations related to several important programs for children and their families.

The Child Welfare League of America is the oldest and largest membership organization with more than 550 child serving agencies and 1200 affiliates throughout North America. Our agencies serve 2.3 million children, youth and their families in need of family support services, emergency shelter, out-of-home care, adoption and teen pregnancy services. Many of the children and youth whom CWLA members serve are deprived, neglected and/or abused; in other words, CWLA agencies work with some of the most troubled and needy children and families in the country.

We are requesting your support with respect to the following two issues:

(1) We recommend that you reject the President's proposal to cap the Title IV-E Foster Care Administrative Program. The Administration would have you believe that administrative costs in the Foster Care Program pay ONLY for what we typically think of as overhead costs. While overhead is a part of these costs, there are other activities paid for which are directly related to the care and protection of children in out-of-home care. These activities, which are commonly referred to as "protections", are mandated by Federal law, federally audited, and fiscally sanctioned if States don't provide them. These protections include:

CASE PLANNING: The federal law mandates that every child in foster care have a case plan describing his/her needs and what is being done to meet those needs.

CASE REVIEWS: The Federal Law mandates that the case plans are reviewed -- either by a court or administrative body -- every 6-months and at 18-months from the date a child enters out-of-home care.

If the States fail to meet these mandates, they are fiscally sanctioned. In fact, over the several years in which HHS has been auditing States, the Federal Government has collected $16 million as a result of compliance reviews.

One explanation for the growth that has occurred in administrative costs over the past ten years (FY 1981 to 1991) relates to the fact that in 1980, P.L. 96-272 was enacted which, for the first time, required states to provide these protections.

In testimony before the House Ways and Means Subcommittee on Human Resources April 5, 1990, HHS Inspector General Kusserow testified that: (1) for the four year period ending FY 1988, foster care administrative costs increased 180% (vs. HHS' claims of 2800% increase); (2) less than 20% of these costs went to pay for what is typically regarded as administrative costs; and, (3) all were "allowable" as defined by HHS.

CWLA submits that all of these activities are appropriate and good casework, designed to insure that the rights of children are protected in out-of-home care. If administrative costs as currently defined are capped, then children will no longer be guaranteed the protections intended under P.L. 96-272.

CWLA, therefore, urges this Subcommittee to reject the President's proposal to cap Title IV-E Foster Care Administrative Costs.

(2) Minority Children Placement Program and Post-Legal Adoption Services: Since its inception in 1978, the Adoption Opportunities Program has successfully supported activities aimed at increasing adoption opportunities for all children in need of permanent, adoptive homes, and at ensuring the adoption of children with "special needs" by seeking to eliminate barriers to adoption. In 1988, this legislation was amended to authorize two demonstration programs: **Minority Children Placement Program and Post-Legal Adoption Services**, which were initially funded at a total of $1 million to be divided equally between the two programs. An indication of the need and interest in those programs is that, in FY 1989, the Department of Health and Human Services (HHS) received 70 proposals from 32 states totaling $5.2 million for the Minority Childrens Placement Program (see "Appendix A" for state abstracts of many of the Minority Children Placement proposals submitted). HHS received 58 proposals from 35 states totaling $5.8 million for Post-Legal Adoption Services (see "Appendix B" for abstracts of many of the Post-Legal Adoption services proposals submitted).

CWLA urges that appropriations for FY 1991 be increased to a total of $10 million, with $5 million appropriated for the Minority Childrens Placement Program and $5 million appropriated for Post-Legal Adoption Services.

(A) The Minority Childrens Placement Program provides demonstration funding for targeted efforts designed to recruit adoptive families for minority children in foster care who have the "permanency planning" goal of adoption. This program was originally funded at $500,000 in FY 1989, and increased to $800,000 in FY 1990.

National statistics indicate that minority children have a more difficult time in achieving permanence through adoption than non-minority children. It is estimated that roughly one-half of the 31,000 children with special needs currently free for adoption and awaiting placement are minority children. In addition to being disproportionately represented in foster care, the median length of stay for minority children in care is one-third longer than the national median.

There is much evidence that where targeted comprehensive efforts are made, adoptive families for minority children are identified, surprisingly often without much difficulty. The next hurdle in the process comes in the actual finalization of the adoption.
Once a family is identified, the agency must interview and "study" the family to insure that it is well suited to meet the needs of the child. The New York Council on Adoptable Children (COAC) testified in 1987 before the Select Committee on Children, Youth and Families that they had, at that time, identified 424 families for 3800 waiting children in New York City. These families waited an average of 2 years and three months before a child was actually placed with them. As a result of such delays, COAC testified that up to 25% of the families dropped out of the program. The obvious affect is that some of these children who might otherwise have grown up in a permanent adoptive home continued to wait and grow up instead in foster care.
The $5 million CWLA is requesting for the Minority Childrens Placement Program would help to address these issues.

**(B) Post-Legal Adoption Services:**

The Adoption Opportunity Program has been highly successful in helping to place children with special needs with adoptive families. However, once the adoption is finalized there is no system of support to adoptive families. Generic social and mental health services fall far short of the unique needs of adoptive families who seek help in order to stay together. CWLA agencies report that more and more adopted children are being placed in residential care because there are no alternative services available. In 1986, CWLA conducted a survey of 107 group care facilities located in 11 states representing 4100 children. The survey found that approximately 10% of children in care were adopted. Of this number, 48% had been adopted as infants and 62% had been adopted as older, possibly "special needs" children.

Around the same time, a survey was done by the American Association of Children's Residential Centers (AACRC) and the National Association of Psychiatric Treatment Centers (NAPTCC) of 51 facilities which had similar findings: 14% of children in residential care were adopted; 51% were adopted as infants and 49% were adopted sometime after infancy. What is most striking about these data is that only 2 percent of the total U.S. child population under age 18 are adopted children and yet 10% to 14% of children in these surveys were in residential placements.

The Post Legal Adoption Services Program, authorized under the Adoption Opportunities Program, would provide funding for a range of less costly alternative services for adoptive families: individual and family counseling, support groups for families, as well as training for agency staff on adoption issues.

All of the 58 applicants from 35 states who applied for grants echoed the need for more of these services. Some states did not apply because they were discouraged by the low amount of money available. Adoption specialists say that children are being placed today who probably would not have been adopted 15-20 years ago, and that the current system is not able to adequately support the acute needs of these new adoptive families. The $5 million CWLA is requesting would help to put this support in place for adoptive families.

APPENDIX A

## Abstracts Of Selected Proposals For The Minority Children Placements Program Submitted To The Department of Health and Human Services in 1989

(The following were selected because they are from states of members of the Appropriations Committee. A full list of abstracts is available on request)

### Mississippi

Mississippi Children's Home Society and Family Services Association sought a grant to recruit adoptive families for minority children by organizing a network of minority ministers to help recruit families throughout the state. The majority of children free for adoption in Mississippi are minorities. **This application was not funded.**

### Pennsylvania

The Adoption Center of Delaware Valley submitted a proposal to identify and train special advocates who would recruit 200 families to adopt minority children. Seventy pêrcent of the children awaiting adoptive homes in the Delaware Valley are minorities, and the longer they remain in foster care the more difficult it will be to find adoptive families. The project would also launch a media campaign to dispel myths about adoption and provide support to prospective families from recruitment through placement. **This application was not funded.**

The Council of Three Rivers American Indian Center an off-reservation adoption agency provides adoption services to all minorities. The proposal they submitted would develop networks of existing adoptive families who would help recruit other minority families. **This application was not funded.**

Three Rivers Adoption Council sought a grant to recruit families for minority children who are seven years old or older and who have moderate to severe developmental disabilities. A major product of this project will be a Training and Assessment Manual with a dual sensitivity to cultural and disability issues. **This application was funded.**

### Washington

Medina Children's Services in Seattle submitted a proposal to develop church and community groups to recruit minority adoptive families. The project would also mobilize current minority adoptive families to help recruit others. Training for staff in cultural issues and a media campaign to alert the public as to the need for minority families willing to adopt was also a part of the project. **This application was not funded.**

The Seattle Indian Center sought a grant to develop a computerized networking system with other agencies that could help identify minority families for children awaiting placement. **This application was not funded.**

**APPENDIX B**

## Abstracts Of Selected Proposals For Post-Legal Adoption Services Submitted To The Department of Health and Human Services in 1989

(The following were selected because they are from states of members of the Appropriations Committee. A full list of abstracts is available on request)

### Idaho

The State Department of Health and Welfare, Family and Children's Services Division, sought a grant because they see that children with special needs who are adopted reappear in the system as clients in the child welfare system, including protective services and mental health services. Adopted children are overrepresented in foster care and group residential systems in the state by 10-15 percent, compared to the 2-3 percent nationally. When families present their special needs adoption as the service need, services are limited to brief counseling and referral to the private sector for private therapy at their own expense. **This application was not funded.**

### Iowa

Four Oaks, a private, comprehensive children and family services agency sought a grant for post-legal adoption services to serve Eastern Iowa families who have adopted children with special needs. They estimate that 25 percent of special needs adoptions are "unsatisfactory." Iowa does not collect statistics on how many adoptions are disrupted each year. **This application was funded.**

(The 1988 Annual Report of the Iowa State Foster Care Review Board shows that of the children adopted during that year, **79 percent** had been placed in two to eight foster homes prior to the adoption; **85 percent** were over three years of age at the time of the adoption; and **22 percent** had a learning or behavioral disability, or were mentally retarded. State officials at the Department of Human Services believe the above characteristics predict that the families will experience difficulties and will need ongoing services to prevent disruptions in the adoptions).

### Mississippi

The Mississippi Department of Human Services sought a grant to minimize disruption of adoptive families by offering post-legal adoption services statewide. The population of children awaiting adoption is almost exclusively comprised of special needs children. The state believes that historically services rendered to prevent disruption or dissolution have been delivered haphazardly in the midst of crisis. The Department was proposing to develop and coordinate comprehensive services so that future placements can be made responsibly and already formed families will be able to access these necessary services. **This application was not funded.**

### New Hampshire

The State Of New Hampshire Division For Children and Youth Services sought a grant to develop respite care, family support groups, case management and training for adoptive families. The state receives many requests from families who adopted children at a young age who are now adolescents and in juvenile detention or mental health facilities. The state is unable to respond and believes that some of the problems could be avoided if services were available. **This application was not funded.**

**Pennsylvania**

"Philly Kids Play It Safe",Tabor Children's Services, Concern, Family Services of Burlington County, and Parents Anonymous of Delaware submitted a joint proposal with the goal of preventing adoption disruptions due to the sexual abuse history of the adopted child. Staff will be trained to conduct post-legal adoption support groups for families experiencing the after-effects of sexual abuse on their adopted children. **This application was funded.**

A private agency serving a multi-county area of Eastern Pennsylvania sought a grant to develop a continuum of post-legal adoption services including family therapy, training, peer support, case management and a video training package to serve adoptive families of special needs children. The project would feature cooperation among public and private agencies and parent organizations. **This application was not funded.**

**South Carolina**

The University of South Carolina, College of Social Work submitted a proposal to supplement the program development activities of the "Consortium of States to Increase Special Needs Adoption". The project will develop and deliver educational services both to adoptive families and to trainers who will in turn work directly with families. **This application was funded.**

**Texas**

The Texas Department of Human Services submitted a proposal to provide for the implementation and delivery of post-adoption services through training of adoption and mental health professionals.The project would produce a resource handbook for adoptive families as well as ongoing training for professional staff. he Department reports that at any given time there are about 600 children awaiting adoption. Most are likely to have experienced numerous foster care placements. During the last 10 years, about 8,000 children have been placed by the department in adoptive homes. In 1988, DHS placed 634 children, most of whom could be described as special needs children because of past histories of severe trauma, including abuse and neglect; of these 634, 86 adoption disruptions occurred. Families who adopted children as infants or small children are returning to request services for these children that are not now readily available. Service professionals have come to recognize that untreated or inappropriately treated victims may have future problems. **This application was not funded.**

**Washington**

A private agency submitted a proposal to increase the availability of post-legal adoption services to families within underserved communities throughout the state. The agency has found that substance abuse and AIDS are creating special needs children. In the Pierce County area alone, 10 to 14 percent of all live births were babies exposed to cocaine prenatally. It is estimated that 75 percent of these children will require out-of-home placement. The agency reports that 93 percent of all placements made in the Northwest Region were either over two years of age, experienced multiple foster care placements, experienced abuse or neglect, were exposed to drugs before birth, or were physically or mentally handicapped. Post-adoption services which currently exist in some areas would be broadened to include areas which have clearly articulated the need for these services. **This application was not funded.**

A private agency sought a grant to develop a post-legal adoption services model for the Seattle area. To date, post-legal adoption services have been provided only in response to specific requests when families are in crisis, and have been provided by a variety of staff people. The project would develop a curriculum to provide training to mental health providers; provide clinical counselling to families and develop a family resource directory for adoptive families. **This application was not funded.**

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## STATEMENT OF THE LOS ANGELES UNIFIED SCHOOL DISTRICT

First I want to thank this Committee for restoring the funding levels of the Refugee Targeted Assistance (RTA) and Refugee Employment Social Services (RESS) budgets for the last fiscal year of 1990, after the Administration had initially recommended a drastic cut of some 70%. Since refugee admissions were increasing by 37% at the time, it made sense when you at least funded the same amount as 1989.

Second, I want to express my support for this year's Administration 1991 budget recommendations for the amounts of $37 million and $70 million respectively for RTA and RESS, which are the same amounts as those finally funded for 1990. Although the continuing high number of incoming refugees clearly justify additonal funds for their resettlement, this recommended amount (considering the Federal Budget situation) will maintain a bare minimum program of employment directed services to help some refugees in their quest for a self-supporting life here.

However, I do want to point out the need for the Cash and Medical Assistance Budget to be increased to $275 million (the 1988 level) from the Administration's requested $201 million. Since 1986, this item has been continually cut, unfairly shifting the burden of this refugee resettlement cost to State and local governments. As our Country (including Citizens, Congress and President) deems it a worthy American cause to rescue refugees from persecution and death to bring them to a life of freedom, then we must follow through on our Federal responsibility to properly resettle them, which includes paying for their subsistence costs until they become self-supporting.

Last. I want to express support for distributing the entire RTA and RESS funding according to a standard formula. With the minimal amount of funding available, that formula should be based upon refugee need for social and employment directed services, ie. the relative percentage of newly arriving refugees on welfare living in a certain area or State compared to the total Nationwide. There should be no special projects funded off the top, but instead, States should fund such projects out of their own standard allocation. Also, because local communities are best positioned to determine local refugee needs and practical solutions, the Federal Office of Refugee Resettlement's discretionary and demonstration projects should be limited to 15% at most. In summary, the limited amount of RTA and RESS funding needs to be utilized in such a way to obtain maximum results among the greatest amount of refugees. It is by using a standard allocation formula, without special projects, that we can accomplish the most equitable and effective use of this limited funding.

Thank you for your consideration of this testimony. We in the refugee community appreciate your committment toward an adequately funded and equally distributed Refugee Resettlement Budget for 1991. It will enable our local communities to successfully provide refugees, our newest Americans, with the social and employment directed services that they need for self-sufficiency.

# LOW INCOME HOME ENERGY ASSISTANCE PROGRAM

## STATEMENT OF THE AMERICAN PUBLIC POWER ASSOCIATION

The American Public Power Association (APPA), the national service organization representing more than 1,750 publicly owned electric utilities, is pleased to submit this statement to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies in support of a significant increase in the Low Income Home Energy Assistance Program (LIHEAP) appropriation.

The severity of the winter of 1989 has served to remind us that LIHEAP is still an important lifeline for approximately 5.8 million low income families struggling to pay their utility bills. The sub-zero weather conditions earlier this winter increased the demand for heating fuel and escalated fuel prices. Because most LIHEAP households receive a fixed allocation of funds, this fuel price escalation resulted in a reduction of LIHEAP benefits to all customers. Many households exhausted their annual benefits allocation and were forced to choose between feeding their families and paying their utility bills. Some states depleted their energy assistance program funds, prompting the introduction of H.J.Res. 455/S.J.Res. 261 to appropriate an additional $300 million for the energy assistance program.

This past winter is just one example of the importance of increasing the LIHEAP appropriations level. Since the programs peak $2.1 billion budget in 1985, LIHEAP has undergone severe budget cuts. This year, the Administration has cut LIHEAP by 25 percent, placing the fiscal year 1991 funding level at $1.05 billion, down from $1.39 billion in fiscal year 1990.

Due to these budget cuts, states must stretch fewer dollars to meet the needs of more people. These constraints have forced state administrators of LIHEAP to consider cutting heating benefits, reducing the number of LIHEAP eligible households, minimizing weatherization program funding -- which in the long-run is counterproductive -- and using oil overcharge funds to supplement the LIHEAP program. Although Congress has repeatedly used the existence of oil overcharge funds to justify reduction in LIHEAP funding, many states have nearly depleted these funds.

In response to the cuts in the LIHEAP budget, public power systems throughout the country have developed their own programs to assist low income households in paying their utility bills. Los Angeles Department of Water and Power (LADWP), the largest publicly owned utility system -- serving over 1 million customers -- estimates that more than 300,000 customers qualify for energy assistance programs. Working with the local United Way chapter, LADWP has developed "Project Angel." By checking off a designated box on their utility bills, participants in this project agree to donate specified amounts of money to assist others in paying their utility bills. The project has successfully supplemented the LIHEAP program, and LADWP is now hoping to develop a new program involving corporate donations.

Many other public power systems have initiated similar programs while some systems have developed different methods to assist those in need. For instance, Seattle City Light has initiated a program to lower rates for low income households. Those households whose incomes are equal to or less than 125 percent of the national poverty level, receive an automatic 40 percent reduction in their utility bill.

Although there are many local projects aimed at low income families in need of energy assistance, there is still a need for federal aid. The Low Income Home Energy Assistance Program was created in 1980 to close the gap between the amount of money a low income household can afford to pay for fuel and the actual utility bill. Reductions in the funding for this crucial program would only serve to erode its original purpose and make it increasingly more difficult for those in need to survive. Energy is an essential service in providing and achieving an adequate standard of living. Absent adequate funding, LIHEAP will be unable to fully meet that goal.

## STATEMENT OF THE NATIONAL FUEL FUNDS NETWORK

This statement responds to Senator Specter's request for additional information concerning the need for funds for the Low Income Home Energy Assistance Program (LIHEAP). This response is derived principally from the testimony on LIHEAP reauthorization before the House Subcommittee on Human Resources (Education & Labor Committee) of Ms. Janet Parrish, Chairperson of the National Fuel Funds Network and Executive Director of the Utility Emergency Services Fund (UESF) of Philadelphia. The experience in Philadelphia exemplifies, in most respects, that of the country at large.

It is instructive to review the funding experience of LIHEAP over the last decade.

**PROFILE OF THE LIHEAP PROGRAM FY 1981 - FY 1989*/**

| FY | FUNDING (billions) | AVERAGE BENEFIT | HOUSEHOLDS SERVED**/ |
|---|---|---|---|
| 1981 | $1.85 | $213 | 7.1 million |
| 1982 | $1.875 | $202 | 6.3 million |
| 1983 | $1.975 | $225 | 6.8 million |
| 1984 | $2.075 | $236 | 6.8 million |
| 1985 | $2.1 | $242 | 6.8 million |
| 1986 | $2.01 | $231 | 6.7 million |
| 1987 | $1.825 | $217 | 6.8 million |
| 1988 | $1.53 | $217 | 6.2 million |
| 1989 | $1.383 | $202 | 5.9 million |
| 1990 | $1.393 | N/A | N/A |

NOTE: Cumulative reductions suffered by LIHEAP from FY 1986 - FY 1990 total $1.9 billion.

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*/ Prepared by Helen Gonzales, Staff Attorney, National Consumer Law Center, Washington, D.C.. All data from HHS reports on state implementation of LIHEAP.

**/ According to most recent HHS LIHEAP Annual Report to Congress, for FY 1988 program, estimated number of eligible households ranges from 17.9 million (under stricter state income standards) to 24.8 million (under the federal maximum income standard).

The cuts in LIHEAP in recent years, as reflected in the above table, have directly resulted in extreme hardship to many in the LIHEAP-eligible population. Only about 30% in that group now receive LIHEAP assistance in paying their fuel bills; 900,000 households, consisting of 2.7 million people, were dropped from the program from FY 1987 to FY 1989. Benefits per household in 1989 were 8% below 1987 and 20% below 1985. Contributions by local voluntary fuel funds such as USEF, while extremely useful in supplementing LIHEAP benefits, are far from adequate to fill these gaps.

Turning to the experience in Philadelphia, the realities faced by UESF and the clients it serves each day should definitively shatter anyone's misconceptions that the energy crisis of the poor is a thing of the past. Despite the existence of LIHEAP, UESF, weatherization programs and the various payment plans and customer assistance programs offered by local utilities, low income households still experience termination of utility service. It should be noted that, in light of strict winter termination moratoria, these shut-offs, for the most part, occur during the period from April through October each year. While it is therefore true that many low-income households who are customers of regulated utilities will not have their heating service shut off during the cold weather months, the existence of such moratoria in many states in no way provides a complete or meaningful solution for the problem, as some may assume. On the contrary, the pattern of the timing during which the bulk of utility terminations occur merely serves to underscore the year-round nature of the problem. Many of these warm weather shut-offs stem from unpaid bills from the prior heating season; yet when they occur, the LIHEAP program is closed down, leaving only the private fuel fund to attempt to respond to these needs.

Households who cannot raise sufficient funds to arrange for restoration of their utility service in time for the next heating season face serious and chilling choices. This bitter reality was amply demonstrated by the series of well-publicized tragedies which occurred around the country during December 1989 and January 1990, involving absence of home heating or the use of potentially dangerous alternatives. Three of these occurred in Philadelphia, and resulted in the deaths of three adults (two of them elderly) and five young children (only one of whom was over the age of three) in the space of just a few weeks.

The two senior citizens froze to death in a home which used oil heat; their tank was empty. Apparently, they had no telephone with which they could have reached out to the LIHEAP or the Crisis program to obtain the necessary emergency supply of oil, and the neighbors realized -- too late -- that they had not seen an oil truck make a delivery for some time. Obviously, winter moratoria offer no protection whatsoever to the 30% of low-income households who heat with unregulated fuels; LIHEAP is their only lifeline.

In the other two situations, the electric and/or gas service had previously been terminated for unpaid bills, and the households were using the potentially hazardous alternatives that too many low-income households depend upon for survival: candles, kerosene space heaters and illegal connections to the electrical service of the neighboring property. Reacting to one of the resulting fires, a neighbor told a newspaper reporter:

> They were good neighbors. The only problem was, they were poor and they didn't have no heat.

For how many countless other American households is this their "only problem"? How many more must freeze to death--or, in other times and climes, die from heat exhaustion--before there is a national recognition that the low-income energy crisis still exists?

The devastating magnitude of this crisis can be glimpsed in statistics compiled by UESF each year. The following data are extracted from annual surveys performed just before the onset of winter by the Philadelphia utilities.

| | Total households shut off | Vacant dwellings | Dwellings occupied but unheated | Households using alternate htg. source |
|---|---|---|---|---|
| Dec. 1989[*/] | | | | |
| PGW | 6,207 | 1,135 | 737 | 2,369 |
| PECO | 3,373 | 1,644 | 8 | 113 |
| Dec. 1988 | | | | |
| PGW | 6,228 | 1,519 | 923 | 2,016 |
| PECO | 3,067 | 982 | 18 | 217 |
| Dec. 1987 | | | | |
| PGW | 7,712 | 1,149 | 794 | 1,946 |
| PECO | 3,010 | 1,129 | 18 | 163 |
| Dec. 1986 | | | | |
| PGW | 5,847 | 1,108 | 152 | 1,414 |
| PECO | 2,420 | 767 | 15 | 62 |

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[*/] (Sources: Reports of the Philadelphia Gas Works and the PA Public Utility Commission's Bureau of Consumer Services).

These data demonstrate the vast number of potential tragedies waiting to occur, where still-occupied homes are totally without any heating source whatsoever and an even larger number make use of potentially dangerous alternative heating sources like those involved in the recent fires. Perhaps even more alarming, they illustrate the connection between loss of heat or utility service and the eventual abandonment of the property. While the causes of homelessness in our society are many and complex, and certainly cannot be attributed to loss of heat or utility service alone, according to a recent study by Temple University for the Coalition on Homelessness in Pennsylvania, loss of utility service was cited as the precipitating cause of homelessness in nearly 10% of the cases.

It is important also to stress that the foregoing data vastly understate the scope of the problem, since they are based on a "snapshot" at one point in time and capture the results only for those properties to which service was shut off within the preceding year. Extrapolating from these data, together with statistics compiled by Philadelphia's Low Income Weatherization Assistance Program and its cold weather Heater

Repair Hotline program, it is estimated that some 25,000 low-income Philadelphia households have abandoned the use of their central heating systems (whether due to termination of service for unpaid bills, inability to afford the cost of the fuel required for that central heating system, or an unsafe or inoperable furnace) and are therefore relying on space heaters or ranges to heat their homes.

The clear implication of the statistics and other information presented here is that the amount of federal funding made available for LIHEAP is far from adequate to meet the need. The result? Good people--your constituents, our neighbors--suffer unbelievable hardship every day as they struggle to meet their basic needs on fixed and very low incomes, and neighborhoods deteriorate as otherwise usable housing is abandoned.

It has been repeatedly observed that the typical low-income household has to devote 15% of its income to cover heat and energy bills--four times the percentage the typical middle income family must pay. For the poorest of the poor, the burden is even higher. USEF has found that, with an average annual income of only $5,600, its clients would have to devote one-third of their incomes to cover essential home energy costs, which average about $1,800 per year for gas, electric and water service. Working with a monthly income that averages only $470, our clients must contend with not only energy bills, but housing costs (which we conservatively estimate at $212), food (another very conservative estimate of $100) and the costs of transportation, clothing and medicine. If monthly utility costs of $150 were paid in full, our typical client household would have only $8 left each month for transportation, clothes and other essentials. It is therefore not surprising that utility and heat bills go unpaid. It is also not surprising that such households desperately need the helping hand extended by LIHEAP and the private fuel funds.

While some may retain the stereotypical notion that the nation's nearly six million LIHEAP recipient households are "undeserving" or "deadbeats", nothing could be further from the truth. LIHEAP, its energy crisis intervention component and the private fuel funds prevent health and life-threatening hardships for our neediest and most vulnerable citizens, as indicated in the following chart:

| CHARACTERISTIC*/ | LIHEAP | CRISIS | UESF |
|---|---|---|---|
| Homeowner | 43% | 39% | 52% |
| Working Poor | 20% | 34% | 20% |
| Elderly | 40% | 17% | 15% |
| Disabled | 11% | 9% | 11% |
| Annual Income Less than $7000 | 65% | 52% | 85% |
| Average Household Size | 2.3 | 3.1 | 3 |

It is my understanding that the foregoing profile of Pennsylvania LIHEAP recipients closely tracks the national profile. Several points stand out sharply from the factors highlighted here:

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*/ Sources: PA Department of Public Welfare LIHEAP and Crisis Statewide Demographic Reports for FY 1990 (as of 1/20/90); Utility Emergency Services Fund Client Profile Report for FY 1990 (as of 12/31/89).

1. A large percentage of the LIHEAP population own their homes.
2. The elderly participate heavily in the LIHEAP cash grant program, in proportion to their percentage of the total low-income population, but are under-represented in the Crisis component.
3. There are a significant number of working people who rely upon LIHEAP assistance.
4. The typical LIHEAP recipient household is a small one, consisting of no more than three persons.
5. The common denominator for LIHEAP recipient households is that they have extraordinarily low incomes, making it largely impossible for them to cope with the costs of essential, basic heat and utility service.

In short, LIHEAP's protections accrue largely to the very old and the very young -- the most vulnerable segments of our population. We are therefore gravely concerned that, because of gross underfunding for the last several years, the LIHEAP "safety-net" is letting greater and greater numbers of needy and deserving households slip through its cracks.

# ALLIED HEALTH

## STATEMENT OF THE SUMMIT ON MANPOWER

The Summit on Manpower strongly urges significant increase from Fiscal Year 1990 appropriations to Allied Health Project Grants and Contracts of the Health Omnibus Extension Act (P.L. 100-607) enacted in 1988. Realizing that radiological science comprises approximately 10% of all allied health in the United States, it is our belief that any assistance in support of education will benefit the profession and help minimize the dilemma we are now facing with the shortages of personnel.

The Summit on Manpower is a collaborative effort of 17 national health care organizations formed to address a common concern - the growing shortage of radiologic technologists and sonographers in the United States. Under the guidance of the American Healthcare Radiology Administrators (AHRA), representatives of the 17 organizations have continued to meet and work together since April 1988 to address and find solutions to the crisis situation regarding the personnel shortages. The Summit is composed of all the professional organizations, certifying boards, and educational accreditation boards representing the radiological sciences, which includes the disciplines of radiography, nuclear medicine technology, radiation therapy technology and sonography. This represents approximately 300,000 healthcare professionals.

Much of the Summit's initial work was directed at validating the widespread perception that a shortage of technologists and sonographers exists. At the November 1988 meeting, a special Task Force on Data presented the results of its exhaustive review of available research and information. Realizing that federal assistance would not be an all exclusive answer to the problem, in subsequent meetings the Summit has actively pursued ways to decrease the rapid advancement of the problem. Through contributions from the organizations and through private funding from industry, the Summit has contracted with a public relations company to produce an outreach program that focuses on methods to market the profession. A survey focusing on the issue of retention was conducted to better assess the career opportunities. An action plan is being developed with long range goals for the individuals, institutions, professional organizations, and physicians to address the problem of staff shortages. A manpower networking resource will soon be published to assist radiology administrators in combating the shortage problem in their individual situations.

In the Fall of 1988, the Summit organizations agreed upon a position and released a statement concluding that "existing data on manpower in radiography, sonography, nuclear medicine technology and radiation therapy technology indicate that the supply of qualified personnel does not meet current demand nor will it meet future needs. Further, the Summit is concerned that without active intervention, patient care and patient services will be compromised. The summit is committed to the development and implementation of action plans which focus on education, government relations, recruitment, and retention." Even with the current activities by the Summit, the position remains unchanged and federal assistance is still needed.

The Summit's Task Force on Data reported on their review of existing data sources to substantiate the conclusion that a shortage does exist. Three types of organizations have data related to the issue: (1) organizations focusing on education; (2) organizations focusing on certification; and (3) organizations focusing on professional issues of which employment is one. Organizations involved in education have data from which supply of personnel for the near future can be assessed; those dealing with certification have data on the current supply of personnel. Several organizations from the third category provided survey data which linked current supply and demand. In addition two government studies were referenced that deal with projected future demand. Current supply information is based on certification data. The following are the numbers of certified technologists (it is estimated that 20-30% of the working technologists are not certified): Radiographers 156,011 (70% in hospitals), Nuclear Medicine 9,491 (90% in hospitals), Radiation Therapy 5,751 (80% in hospitals), and Sonographers 12,550 (66% in hospitals).

Two nationwide surveys conducted in 1988 by the AHRA and the Society of Nuclear Medicine Technologists Section addressed the issue of current supply and demand of technologists. A deficit is noted in every case for which data were collected. Vacancy rates ranged from 3% to 15% in radiography, from 3% to 13% in nuclear medicine technology, from 5% to 21% in radiation therapy technology and from 4% to 17% in sonography. In two surveys, questions asking whether a shortage was thought to exist were included. Respondents to both surveys overwhelmingly felt that a lack of technologists existed. 84% perceived a shortage in radiography, 84% perceived a shortage in nuclear medicine technology, and 91% indicated a shortage in Sonography. These data collected imply that demand exceeds supply in the hospital sector, which in turn accounts for the majority of positions.

The future supply of technologists at the present time is dismal. Since 1985, there has been a 13% decrease in the number of educational programs in radiography and a 25% decrease in the number of nuclear medicine technology schools. Along with the loss in schools has been a marked decrease in the number of graduates. The schools are all running at less than their approved capacity (radiography at 57% capacity, nuclear medicine at 63% capacity, radiation therapy 48% capacity, and sonography at 62% capacity). The number of individuals taking the certification boards continues to decrease yearly verifying that there will be a decrease in future availability of the work force.

A recent government study dealt with manpower shortages in allied health. "Allied Health Services: Avoiding Crises" by the Institute of Medicine projected a growth rate of 65% for radiologic technologists over a twelve-year period. The current rate of increase in radiologic technologists (about 4,000 to 5,000 per year) falls short of the roughly 6,000 per year needed to reach that projection. The decreasing number of examinees will further exacerbate the shortfall.

A major factor in the projected increased need for radiologic technologists is the aging of the U.S. population and the consequent increased health care required. A very significant problem in meeting manpower needs is the parallel aging of the technologist population. The largest percentage of the current technologist population was born in the 1950s. That means that just as the need for additional technologists is peaking, a large population will be preparing for retirement. This trend has the potential to make the shortage extremely severe in the future.

A nation wide shortage of radiographers, nuclear medicine technologists, radiation therapy technologists, and sonographers currently exists. The scarcity of technologists is being felt in essentially all parts of the country based upon data collections. The shortages are predicted to become increasingly severe based upon the current trend in supply and the projected trend in demand. When government projections for increased demand and demographic trends suggesting decreased supply are considered, the potential for an extreme shortage exists in the near future for all the disciplines.

Please consider complete funding for Allied Health Project Grants and Contracts. It is believed that this is a positive start in the right direction for adequate health care in the future. By providing complete appropriations, the Committee will demonstrate its awareness of the existing problems in providing adequate education and training for students in allied health, including the radiological sciences, and in ultimately supporting quality health care.

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## STATEMENT OF THE AMERICAN SOCIETY OF ALLIED HEALTH PROFESSIONS

Dear Members of the Senate Health Appropriations Subcommittee:

The American Society of Allied Health Professions (ASAHP) urgently seeks Congressional support and commitment to move swiftly forward to address an allied health manpower shortage which restricts the quality of health care available in the United States. Specifically, Congress needs to address the:

-Severe current and growing shortages of allied health personnel including occupational and physical therapists, speech-language pathologists, medical record technicians, audiologists, and medical laboratory technologists;

-Underrepresentation of minority persons in the allied health professions;

-Rapid growth in the number of older persons needing the services of allied health personnel, especially in rural areas; and

-Lack of federal programs which support allied health education. During the period 1981-89, there were no federal programs authorized to support allied health education. For FY 1990, only $726,000 in grant money was made available.

Allied health problems can be found in hospitals and other health care delivery settings (e.g., manpower shortages, underutilization), educational institutions (e.g., inadequate funding, lack of visibility, faculty shortages, inadequate scholarship assistance), and in rural, densely populated, poverty-ridden urban areas (e.g., inability to recruit and retain personnel).

## Manpower Shortages

Compelling evidence is available to document the growing magnitude of personnel shortages in allied health. Studies, surveys, and reports by groups such as the American Medical Association, American Hospital Association, American Society of Allied Health Professions, U.S. Department of Veterans Affairs, National Institute on Aging, Medicare Prospective Payment Assessment Commission, U.S. Department of Education, U.S. Department of Health and Human Services, and the Institute of Medicine of the National Academy of Sciences highlight the seriousness of a diminishing pool of allied health personnel and a worsening outlook for the future.

## Faculty Development

Doctoral programs in the allied health professions are needed to prepare additional faculty. New program developement in colleges and universities has been stymied because inadequate numbers of qualified faculty are available to fill vacant positions. Institutions are forced to compete in a game which many are destined to lose. Fellowship assistance is needed to increase the number of faculty at a more accelerated rate.

## Funding For Research

Allied health research is needed to undergird practice in various allied health professions, increase the body of knowledge, and stimulate inquiry into efficacy of practice among various disciplines. Technology assessment of allied health practices is an area of inquiry requiring particular attention. Research funding is also necessary to support the development of scholars and scholarship in allied health educational institutions to ensure a pool of qualified faculty members.

## THE FEDERAL ROLE

It is the belief of the Society and its Board of Directors that the Federal government should, as the largest consumer of health care, play a central role in partnership with State governments and private institutions in reducing shortages of allied health personnel. Furthermore, ASAHP believes that this role should encompass both attracting students (particularly from minority and underserved portions of the population) to academic allied health programs and supporting programs for preparing allied health professionals for careers as academicians.

No Federal programs were authorized specifically to support allied health education during the period 1981-89. P.L. 100-607, the Health Professions Reauthorization Act of 1988, authorized $6 million. The actual appropriation, however, was only $726,000. This money will be used to fund approximately seven grant proposals. It is worth noting that the U.S. Public Health Service received more than 2000 requests for applications and descriptive material. Despite a short turn-around time and the fact that many academic institutions were on semester break at this time of the year, 122 proposals were prepared, submitted, and accepted for review. Obviously, these figures provide a solid indication of the extent of both the need and the interest in conducting projects which have the potential to improve allied health services.

ASAHP believes that the most appropriate venue for the Federal government to affect reductions in the shortages of allied health professionals is through the training grants and student financial programs of Title VII of the Public Health Service Act (PHSA), funded through the annual appropriations of the Departments of Labor, Education, and Health and Human Resources.

## CONVENTIONAL MARKET FORCES ALONE ARE INSUFFICIENT TO ADDRESS PROBLEMS

Public and private interests have joined forces in many States to cope with the problem of an inadequate supply of trained health care personnel. While notable strides have been made, it has become abundantly clear that conventional market forces alone are inadequate. Indeed, the only alternative for many providers is to enter into bidding wars with other health care institutions for a scarce supply of manpower. Given the ominous and relentless acceleration of health care costs, it bodes ill for the overall economy to allow such competition to continue.

Conventional market forces usually focus on supply and demand. While manpower shortages may cause entry-level salaries for allied health personnel to escalate, they will not necessarily stimulate colleges and universities to increase the number of graduates nor will they affect the availability of research funding and funds for doctoral programs to prepare faculty. Currently, market forces are being operationalized by hospitals "to buy" students, i.e., hospitals provide tuition support for students in return for working at these institutions. While students are assisted, this practice does not produce any more graduates.

The Federal government has a valuable role to play in assuring an adequate number of trained personnnel to meet America's health care needs. Assistance is required in the form of providing financial aid to needy students and funding model student recruitment/retention projects. An increase in the number of faculty at training institutions will result in more graduates available for entry into the workforce. Expediting this goal will require financial assistance for those currently pursuing advanced degrees on a part-time basis so that they can attend school full-time. A related consideration is to provide the training necessary for practicing clinicians to make a smooth transition to academia.

As technologies continue to change, proposals should be funded to assist educational programs in readjusting curricula. Creative, innovative ways of training and retraining health professionals need to be developed. Models must be designed to increase the effectiveness of student recruitment efforts, especially among non-traditional students such as older persons, individuals wishing to change careers, and the disadvantaged.

## RECOMMENDED ACTION

For the 101st Congress, ASAHP urges the House and Senate to adopt the following proposal:

1. Appropriate Funds Authorized By P.L. 100-607, the Health Professions Reauthorization Act of 1988 for Allied Health.

Instead of $726,000 for allied health grants and contracts, ASAHP requests an appropriation of the full $6 million for FY 1991: $2 million for grants and contracts; $2 million for traineeships for advanced training of allied health personnel; and $2 million for a new loan repayment program.

We thank you for your attention and consideration.

# CENTERS FOR DISEASE CONTROL

## STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

Dear Mr. Chairman:

The American Society for Microbiology (ASM) would like to submit the following statement for the record on the Fiscal Year (FY) 1991 Budget for the Centers for Disease Control (CDC).

Based on the budget requests made by the Administration for FY 1991, it is our belief that the Centers for Disease Control will have insufficient funds to discharge its responsibilities as the primary agency in controlling disease and providing research and training in the control of disease. The overall increase of 7% falls short of the increase of 12% in FY 1990. The increase for the non-HIV/AIDS portion of the proposed budget is only 2.3%. This does not cover inflation and is less than the 8% increase in FY 1990. We note that significant resources are being allocated for the control of HIV/AIDS and we welcome this continuing effort of the Administration. However, we are extremely concerned about the consistent neglect of the other areas of disease control which are still within the purview of CDC.

1. Sexually transmitted diseases:

For the past several years, the Administration has consistently refused to increase funds for project grants awarded to state and local government authorities to support programs in education, surveillance, testing, outbreak investigation, and the control of sexually-transmitted diseases such as syphilis, gonorrhea, and chlamydiasis. The rising number of syphilis cases is frightening. The number of cases rose 30% in the past two years to the highest number since 1948! In the same two year period, the number of reported congenital syphilis cases rose by the unbelievable rate of 152%! The increase was greatest among blacks and Hispanics, especially in the inner-city population and among "crack" users. How does the Administration propose to control HIV/AIDS if it fails to provide sufficient funds to control other sexually-transmitted diseases, such as syphilis, in our high density urban areas? To cope with this national scourge, the Administration has requested the same amount of money as was approved in the FY 1990 appropriation. The ASM believes that this request is totally inadequate to cope with a problem of such national import. We are losing the war on syphilis and seeing a steady increase of HIV/AIDS in the same population. It is apparent that the CDC will continue to have problems mounting an effective national program against sexually-transmitted diseases. Therefore, we urge the Congress to increase the Administration's budget request for sexually-transmitted diseases by at least $20 million. That should be directed toward state and local programs which are most capable of reaching at-risk populations.

2. **Immunization:**

Immunization of young children has been considered by many one of the most successful activities of CDC in insuring quality of life of infants and children and reducing morbidity and mortality. It has also been the most cost effective method of preventing human disease and reducing health costs. We are concerned that there is virtually no increase requested for project grants over the FY 1990 budget. Therefore, we recommend for FY 1991 an additional $5 million for project grants to maintain the same level of coverage as in previous years, and to support an increase in the efforts of the perinatal Hepatitis B program in inner city and minority populations. Despite the availability of effective vaccines and antiserum, there is still a very high incidence of infections with associated loss of productivity and chronic disease. Support is also needed for implementing the OSHA required vaccination against Hepatitis B for the control of blood borne viral infections in such volunteer organizations as rescue squads, fire brigades and similar public service organizations that are at risk for infection with blood- borne viruses.

Over the past years, there have been several major outbreaks of measles in the nation's colleges and universities. The Society believes that it is necessary to investigate the immunization status of the college age population to prevent recurrence of these major outbreaks and to promote an active vaccination program as well as revaccination for certain age groups that had been vaccinated by nonprotective vaccines. Therefore, we recommend that an additional $40 million be appropriated to carry out the recommendations of the Advisory Committee for Immunization Practices for measles immunizations. We are very concerned that the Administration has not requested funds to increase the vaccine stockpile in 1991. The contention that anticipated decreases in vaccine prices due to the Vaccine Compensation Act will reduce the cost of vaccine for the stockpile is unfounded. We believe that the stockpile of all vaccines should be raised to at least a 26 week supply and should include the Haemophilus influenzae b vaccine. We urge Congress to review this matter in great detail and to consider the reinstitution of funds for the vaccine stockpile at about $6 million.

3. **Infectious diseases:**

Many members of the American Society for Microbiology are practicing clinical microbiologists and physicians specializing in infectious diseases. We at ASM are concerned that due to the inadequate funding, the National Center for Infectious Diseases may not be able to remain in the forefront of developing studies and strategies for the control of a number of emerging and reemerging infectious diseases. Over the past five years, the average increase in appropriations did not stay in step even with inflation.

While exerting great efforts to reduce the cost of hospitalization, the United States has not been able to reduce the incidence of nosocomial infections in US hospitals. If we consider that one third of all nosocomial infections (about 2 million cases per year) can be prevented by appropriate control mechanisms, it is extremely important that community hospitals as well as various extended care facilities are able to call on the experts of the CDC for advice and support in this area. These experts must have the capability to do research in the areas of nosocomial infections, associated causes, strategies of prevention, and biology of microorganisms. Furthermore, the Center must support the education and training of infection control personnel, serve as national consultant, and help develop standards of practice in this arena.

Tuberculosis, a reemerging disease, disproportionately affects minorities including recently arrived refugees from third world countries, as well as elderly and socioeconomically disadvantaged members of our population. Our indicators show that the tuberculosis problem in these groups is worsening and is not being appropriately controlled by our present public health efforts. In order to support the challenge to eliminate tuberculosis from the United States by the year 2010, Congress must support innovative programs. The CDC, in cooperation with state and local authorities, is the obvious leader for administering and developing cost effective programs for identifying high risk groups. Having gravely neglected the support of these programs over the past years, Congress ought to express its interest in controlling this scourge and in making the United States free of tuberculosis by 2010 by allocating $25 million to this elimination program.

Lyme Disease, a newly recognized infectious disease of worldwide significance, requires additional research and evaluation of preventive control measures as well as laboratory diagnosis. A $5 million allocation will push this program into the realm of reality.

Other infectious diseases which need to be studied by the Centers for Disease Control are non A/Non B hepatitis, adult T cell leukemia/lymphoma caused by HTLV1, causes of fetal death, infections in neonates, and the increasing problems of infectious disease transmission in daycare centers.

Food-borne diseases caused by such organisms as salmonella, campylobacter, listeria, and pathogenic Escherichia coli affect at least 6 million persons annually, and the number of cases continues to rise. Experts from the Centers for Disease Control must be able to coordinate efforts to prevent such problems which have a major impact on the economy of the United States. Again, a $5 million allocation will permit CDC to do basic work and support local and state programs of control and surveillance.

All these programs cannot be supported with the very modest budget requested by the Administration. We strongly urge Congress to consider at least doubling the requested budget for these important infectious disease control programs.

## Conclusion

We believe that the United States cannot retain its leadership role in international health without well trained experts and scientists in our government agencies. Although insufficient funding affects the entire Public Health Service, we are specifically concerned about its effect on the technical, clinical, and epidemiologic expertise of the Centers for Disease Control. The CDC has brought high prestige to our country and has been a major contributor to the resolution of infectious disease problems world wide. We hope Congress will continue to support our colleagues in federal employment in order to maintain a high quality scientific and professional staff.

Congress mandated in PL 100-578, Section 4, that the CDC conduct five studies to determine the effectiveness of the new governmental regulations of laboratories. The results were to be reported to Congress by May 1, 1990. Funding for these important studies, however, has not yet been appropriated. In order for CDC to identify the problems with proficiency testing, standards of personnel, internal quality assurance, effect of inaccurate test results, and the value of tests to the clinician, it is imperative that at least $1 million be allocated.

We welcome the opportunity to work with you and to assist you in any way possible. We urge that budgetary changes be made for the Centers for Disease Control, so that it may perform its assigned functions efficiently and economically in order to comply with the public health charter to protect the health of our nation.

## STATEMENT OF THE AMERICAN HEART ASSOCIATION

*The American Heart Association (AHA) is dedicated to the reduction of disability and death from cardiovascular diseases and stroke. Annually these diseases cause about one million deaths in the United States. More than one in four Americans suffer from some form of these diseases at an estimated cost in 1990 of $94.5 billion in medical expenses and lost productivity.*

*The goals of the Office of Disease Prevention and Health Promotion (ODPHP) and of the Centers for Disease Control (CDC) are of primary importance to the AHA. Many of the AHA programs complement those of both the ODPHP and the CDC. The AHA's Heart At Work program increases employee awareness and knowledge of cardiovascular risk factors and encourages behavior change that will lead to risk reduction. The AHA's Heart Treasure Chest program educates elementary school children about the cardiovascular system. Our Heart Rx program assists health professionals in counseling their patients about prudent life-styles that can lead to improved cardiovascular health. The AHA's Physicians' Cholesterol Education Program assists doctors in counseling patients on controlling blood cholesterol levels. The respective disease prevention and health promotion activities of the AHA, the ODPHP, and the CDC are aimed at reducing the overall costs of cardiovascular disease. The AHA is pleased to provide you with our comments and FY 1991 funding recommendations for the ODPHP and the CDC.*

### *OFFICE OF DISEASE PREVENTION AND HEALTH PROMOTION (ODPHP)*

*The ODPHP, the Federal office responsible for policy oversight and coordination of prevention activities of the agencies of the Department of Health and Human Services (DHHS), fosters the development and assimilation of similar activities in the private sector, services a national information center to facilitate access to and exchange of information concerning health promotion and disease prevention, and supports projects, conducts research, and disseminates information about health promotion, preventive medicine, and physical fitness.*

*In 1979, the ODPHP issued the first Surgeon General's Report on Health Promotion and Disease Prevention, entitled Healthy People, the initial Federal document describing a national commitment to improve the health of this country through disease prevention. It laid the ground work for what has become the cornerstone of the programs of the ODPHP -- implementation of 226 objectives outlined in the 1980 report entitled Promoting Health/Preventing Disease: Objectives for the Nation. The ODPHP Prevention Policy Staff is responsible for assessing and reporting on the Nation's progress in attaining these objectives.*

*Currently, a central focus of activity at the ODPHP is the coordination of a grassroots effort, involving all 50 states and over 200 national organizations, to develop a set of national health objectives for the year 2000. Healthy People 2000, a revised 1979 Healthy People, will be issued at a national meeting in September along with the final version of the year 2000 objectives. The ODPHP continues to monitor, track data, and stimulate implementation of programs in support of the 1990 Health Objectives.*

*Other components within the ODPHP include the Clinical Services Staff, which coordinated the development of the U.S. Preventive Services Task Force's Guide to Clincial Preventive Services, an* *assessment of the effectiveness of 169 interventions. The Nutrition Staff works to strengthen DHHS's capabilities and national leadership in nutritional research and monitoring, educational services and training, food safety and quality, and international nutrition. The Health Communication Staff operates the ODPHP's National Health Information Center, the publication and data management center.*

*The President's FY 1991 budget recommends $4.461 million for the ODPHP This mere .47 percent increase above the ODPHP's FY 1990 funding level of $4.440 million does not cover the cost of inflation. It would jeopardize the continuation of the following prevention and coordination activities:*

*o year 2000 National Health Objectives, including cooperative agreements with national membership organizations to tailor the Objectives for special populations, professions, and settings, technical assistance to state-level Objectives development, creation of implementation programs, coordination of public health and disabilities prevention efforts, and organization of school and children health promotion programs;*

*o a second Surgeon General's Report on Nutrition and Health, in coordination with the U.S. Department of Agriculture, to emphasize the function of dietary fat in chronic diseases;*

*o complementary nutrition monitoring surveys, with particular emphasis on low income groups;*

*o prevention policy initiatives for the HHS Secretary's Council on Health Promotion and Disease Prevention and support for the Secretary's health promotion for disadvantaged and minority families;*

*o the National Worksite Health Promotion Resource Center, designed to develop models for health promotion programs, provide leadership in defining and solving work and health related matters, and furnish technical support to employers and employee groups;*

*o the U.S. Preventive Services Coordinating Committee, consisting of 25 primary care, medical insurance, and related professional associations interested in preventive service in medical care settings; scientific review of new preventive interventions; and computer software to help physicians provide timely clinical preventive services; and*

*o market research to enhance communication about health education and behavior change, particularly for hard-to-reach youth, the National Health Information Center, and Healthy Older People program coordination with Association of American Retired People.*

*An appropriation of $5.560 million for the ODPHP would allow for the continuation of these services and the initiation of four new initiatives which focus on high risk populations, including children and low income groups. These new programs include:*

*o Healthy Schools, a collaborative venture with the Department of Education, to illustrate how inner city schools can become health-promoting environments for at-risk children;*

*o National Fitness and Nutrition Public Education Program, to stimulate dietary and exercise modification among hard-to-reach at-risk populations for chronic diseases and related premature death;*

*o Communication of Health Risks, to educate the public about the safety and dangers of environmental exposures, clinical preventive interventions, and personal behaviors; and*

*o Healthy Patient Initiative, follow up to the U.S. Preventive Services Task Force's Guide to Clinical Preventive Services, creating and distributing software packages and background for clinical health care* *providers and developing, testing and disseminating curriculum material for graduate medical education and residency programs.*

## *CENTERS FOR DISEASE CONTROL (CDC)*

*The CDC is the Federal agency of the U.S. Public Health Service responsible for disease prevention and health promotion. CDC works with state and local health departments, other federal agencies, and voluntary, professional and international organizations in assisting during emergencies and in developing programs to understand the causes of disease and prevent their occurrence. CDC's programs focus on changing lifestyles and other factors that contribute to disease.*

*In October 1988, CDC established a new center committed to fighting chronic diseases which cause 1.3 million deaths annually and diminish the quality of life for millions of Americans. The new Center for Chronic Disease Prevention and Health Promotion is dedicated to forging a national program to prevent unnecessary death and disability associated with chronic diseases and to promoting healthier lifestyles. Fighting chronic disease means targeting the diseases and the risk factors. Major cardiovascular disease risk factors that result from modifiable lifestyle habits include cigarette smoking, high blood pressure, and elevated blood cholesterol. The CDC has intensified its efforts to combat all these potential killers.*

*As a result of Congressional support in FY 1990, the CDC has implemented a number of innovative projects and enhanced programs. Highlights of some of these activities and accomplishments follow.*

*o Developed "Smoking and Health: A National Status Report," providing information for each state on the health and economic impact of smoking, current legislative measures to control smoking, and smoking cessation and prevention programs.*

*Each year over 390,000 Americans die from smoking-related causes. However, CDC's Office on Smoking and Health (OSH) has had virtually no increase in funding for the last seven years. Due to the partial sequestration, the OSH's FY 1990 appropriation has dropped to $3.4 million. Calculated in terms of 1966 dollars, the OSH now has half of the purchasing power it did 25 years ago. The American Heart Association recommends an FY 1991 appropriation of $13.5 million for the OSH.*

*o Helped 45 states and the District of Columbia track cardiovascular disease risk factors.*

*o Assisted 20 states, the District of Columbia, and Palau establish comprehensive chronic disease control programs, focusing on minority and other medically underserved populations. Established in a South Carolina community a model program, "Heart to Heart," to identify prevention activities that influence people to adopt health behaviors that reduce the risk of cardiovascular disease.*

*o Administered to states the Preventive Health and Health Services Block Grant, containing authority for the high blood pressure program and more recently for cholesterol screening, detection, referral, and follow-up activities. Funding for this block grant has not increased since its inception in 1982.*

*o Supported diabetes control programs in 30 states. Annually over 300,000 persons die from the complications of diabetes, with cardiovascular disease the leading cause of death. CDC helps administrators of these programs apply existing knowledge and technological advances to treat and control* *hypertension and promote smoking cessation, exercise, weight loss, and prudent diet among diabetics.*

*o Initiated a program to improve the eating habits of students nationwide. Guidelines will be written for nutritional education and for the proper components of healthful school lunches. This program actively involves parents and the community in their children's nutrition, both in and outside of school.*

*The CDC has made major contributions toward educating children about the benefits of a healthy lifestyle. Their two comprehensive school health curricula, Growing Healthy, for elementary school children, and Teenage Health Teaching Modules, for high school students, are the most widely used health education curricula. Such school health educational programs are effective in preventing young people from making unhealthy lifestyle decisions that increase the risk of heart disease and other chronic illnesses. A major nationwide evaluation conducted by the CDC showed that comprehensive school health education has resulted in a 37 percent reduction in the number of seventh-grade students who begin to smoke.*

*To win the battle against cardiovascular and other chronic diseases, young people must be taught to adopt healthy lifestyles and avoid unhealthy habits that put them at risk for disease. Therefore, children must have the benefit of quality health education at an early age. The CDC has built a strong national program in school health education. However, until FY 1990 most of the resources for this program targeted activities to prevent the spread of AIDS. AIDS education in the context of comprehensive school health education is commendable, but it is equally important to teach methods to maintain health and to prevent cardiovascular diseases and cancer, the chronic diseases Americans are most likely to acquire.*

*The AHA applauds the Senate Appropriations Committee's FY 1990 report language "allocating $3.5 million in support of comprehensive school health education." We urge this Subcommittee to again provide support for comprehensive school health education by expanding school health programs to promote the complete array of healthy behaviors.*

*The CDC's efforts to fight chronic disease demonstrate their ability to develop effective programs. The AHA recommends an appropriation of $193 million for Chronic and Environmental Disease Prevention of which $111 million is for chronic disease activities, including $13.5 million for the Office of Smoking and Health. This level of funding will strengthen CDC's core program for chronic disease, enabling them to help states provide leadership in the prevention of cardiovascular and other chronic diseases.*

*Hypertension and elevated blood cholesterol levels are leading risk factors for cardiovascular disease. The Health Omnibus Programs Extension Act of 1989, Public Law 100-607, reauthorized the Preventive Health and Health Services Block Grant, which contains authority for the high blood pressure program, and now for cholesterol screening, detection, referral, and follow-up activities. The AHA recommends for the Preventive Health and Health Services Block Grant Program an appropriation of $149 million, a $65 million increase over the FY 1990 appropriation.*

*The AHA urges this Subcommittee to provide sufficient FY 1991 funds for the ODPHP and the CDC. Important prevention and coordination activities must be enhanced so that the ODPHP, CDC, the American Heart Association and other organizations involved in preventive health activities can continue to have a downward effect on the mortality and morbidity rates from cardiovascular and other diseases.*

# NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY AND HEALTH

## STATEMENT OF THE ASSOCIATION OF UNIVERSITY PROGRAMS IN OCCUPATIONAL SAFETY AND HEALTH AND THE NATIONAL OCCUPATIONAL SAFETY AND HEALTH ASSOCIATION

Mr. Chairman:

I am Roy Albert, M.D., the President of the Association of University Programs in Occupational Safety and Health (AUPOSH) and I am Roy M. Buchan, Ph.D., the President of the National Occupational Safety and Health Education Association (NOSHEA).

The purpose of this statement is to urge you and your committee to consider our views concerning the need for additional funding for the National Institute for Occupational Safety & Health (NIOSH). We request that it be made a part of the permanent hearing record of your committee's consideration of the Labor-HHS-Education appropriations bill.

The Association of University Programs in Occupational Safety and Health (AUPOSH) represents the 14 regional university-based Educational Resource Centers (ERC's) which are multi-disciplinary programs that operate under training grants from NIOSH.

The National Occupational Safety and Health Education Association (NOSHEA) represents some 25 additional regionally based university single-disciplinary programs in occupational safety and health professional development and education. NIOSH also provides training grants to these single-discipline project programs.

Thus, the combined ERC and single-discipline programs involve 49 university-based programs that account for nearly all of the professional development and education in the field of occupational safety and health. (See the attached listing of all 49 university programs).

The ERC program, launched in 1977, is intended to carry out the mandate of the Occupational Safety and Health Act to ensure an adequate supply of trained professionals in the multidisciplinary fields of occupational medicine, industrial hygiene, occupational health nursing, and occupational safety. A research training program at the regional ERCs was subsequently mandated by the Congress; in part to attract graduates into academic teaching and research, an area of significant shortage.

In addition to the ERC's graduate academic training programs, an extensive continuing education and outreach program is offered which, over the last five years, has reached an estimated 100,000 people. As indicated above, NIOSH also provides training funds for about twenty-five single-discipline project grantees at other academic institutions out of its training budget, currently at $10,461,000 for Fiscal 1990. For Fiscal 1991, the Administration's budget request reflects no increase in the NIOSH training budget, a fact which causes us serious concern.

We are well aware that your committee has, over the past nine years, shared our concern with the growing shortages of trained occupational health and safety professionals to deal with the increasingly complex health hazards of American workers. For six consecutive years, the previous Administration requested ZERO funding for occupational safety and health training programs. The Congress, on the other hand, has kept the programs alive in the face of severe budgetary constraints.

However, the long span of underfunded training programs has taken its toll. A majority of ERC and single project grant faculty members are non-tenured at their institutions and many promising students withdraw from occupational safety and health careers because of a lack of support and the uncertainty of completion of their training requirements.

Meanwhile, the manpower shortages in key occupational health specialties have been exacerbated. For example, some 90 percent of all of the limited number of occupational medicine practitioners in the United States are the products of the ERC and project grant programs. Yet, in 1989, only 122 physicians received full-time training in occupational medicine at ERCs. The overall impact of Federal budgetary restraints in recent years can be measured by the fact that almost 800 students at the ERCs and project grants graduated in each of the peak budget support years of 1980-1981, when the Federal appropriations were $12.9 million; the current level of graduates is down by nearly two-thirds.

Last year the Reagan/Bush budget for Fiscal 1990 sought drastic cuts of nearly 35% for both NIOSH and the training grant program. Once again the Congress saved the program by restoring the overall NIOSH budget for Fiscal 1990 to $84.6 million, of which $10.4 million was allocated for the NIOSH training budget.

While the Congress last year saved NIOSH from near destruction, the FY 1991 budget request from the Bush Administration is essentially flat with a mere $461,000 increase for research. No additional funds have been requested for the training grant program which, as stated previously, is currently at $10.4 million.

We believe that this is totally uncalled for and, once again, are requesting your help in furthering worker safety and health research and professional development.

Indeed we believe that a minimum acceptable level for the overall NIOSH budget is $100 million for Fiscal 1991, an increase of approximately $15 million over the Administration's request. Of this requested $15 million increase, $10 million should be allocated for NIOSH research, bringing the total research budget up to $84.6 million. The remaining $5 million should be added to the training grant program, raising it to $15.4 million.

This proposal is modest, indeed, compared to where the NIOSH budget should be in light of the past cuts.

We have attached to this statement a table that measures the dramatic impact of NIOSH budget cuts during the 1980's. You will note that the Fiscal 1980 appropriation for NIOSH was $80.4 million (base year), of which $12.9 million was for training and the ERC program. In Fiscal 1991, it would require a NIOSH appropriation of $162 million just to equal the comparable funding of 1980! If these same real dollar figures were to be applied to the training program, an appropriation of $25.2 million in Fiscal 1991 would be required just to keep the same level of training activity as existed in 1980!

Occupational hazards have become increasingly more complex. After extremely hazardous conditions have been identified, it requires highly skilled and broadly trained professionals to evaluate the real causes of injuries and illnesses so that effective and low-cost remedies can be developed and instituted. Our present level of occupational health and training activity in the United States is simply not meeting the demand for such professionals.

It should be emphasized that the annual cost of occupational injuries and illnesses in our country is now estimated to be $200 billion! This amounts to about $1,667 per worker each year! NIOSH's current budget, on the other hand, amounts to a public investment per worker of only about 72 cents!

By comparison, Sweden, for example, in 1988, spent the equivalent of $12.33 in preventive occupational safety and health programs for each worker and Finland invested $12.29 per worker in 1986.

These statistical comparisons are even more startling when measured against the fact that occupational musculoskeletal disorders alone cause the disability of some 12 million U.S. workers annually, while occupational traumatic injuries disable another 10 million workers and result in the annual death of some 10,000 workers. Occupational-induced hearing loss affects some 500,000 American workers a year. Many, if not most, of these fatalities and injuries could be prevented by more effective, professionally-directed safety and health programs.

Much is said today about the need for America to become more competitive so as to reduce our trade and budget deficits. We believe that the prevention of even a modest portion of the annual occupational injuries, diseases and deaths would produce dramatic dividends throughout our economy.

We are acutely aware of the difficult budgetary situation which confronts the Congress and the major effort that is required to get the deficit under control. But we are also convinced that the benefits of an effective occupational health and safety program are critical the Nation's future, and thus warrant additional funding.

We, therefore, urge you and your committee to seriously consider an appropriation for Fiscal 1991 of a total of $100 million for NIOSH activities, including $84.6 million in the research line and $15.4 million in training line of the CDC/NIOSH budget. The latter figure includes a modest restoration of lost ground in the ERC and project grant training programs and a small expansion of the research training effort just recently begun.

We thank you for your past support of our work and sincerely hope that your evaluation of the progress we have made in occupational health and safety education despite limited funding will merit your favorable action on our budgetary request.

### NIOSH BUDGET BASED ON THE RESEARCH AND DEVELOPMENT PRICE INDEX

BASE YEAR -- 1980

| | YEAR | ACTUAL DOLLARS | REAL DOLLARS | EQUIVALENT DOLLARS |
|---|---|---|---|---|
| | 1970 | $10,353,000 | $21,000,000 | $ 39,628,326 |
| | 1972 | 26,267,000 | 47,967,495 | 44,017,183 |
| | 1975 | 33,999,000 | 50,331,606 | 54,298,041 |
| Base Year | 1980 | 80,382,000 | 80,382,000 | 80,382,000 |
| | 1985 | 65,337,000 | 45,840,876 | 114,568,465 |
| | 1986 | 64,551,000 | 43,386,880 | 119,592,340 |
| | 1987 | 70,093,000 | 44,908,380 | 125,590,109 |
| | 1988 | 69,668,000 | 42,235,829 | 132,590,109 |
| | 1989 | 70,355,000 | 40,329,607 | 140,226,399 |
| | 1990 | 84,700,000 | 24,202,584 | 148,079,720 |
| | 1991 | 85,100,000 | 44,700,000 | 162,000,000 |

## NOSHA
## TRAINING PROJECT GRANT AFFILIATES

University of Arizona
School of Health Related
Professions and College of
Medicine

Meharry Medical College
Nashville, TN

Montana College of Mineral
Science and Technology
Butte, MT

Murray State University
Dept. of Safety Eng. and Health

University of Oklahoma
Health Sciences Center

University of Pennsylvania
School of Nursing

University of Pittsburgh
Industrial Environmental Health
Sciences and Graduate School of
Public Health

Texas Tech University
Dept. of Industrial Engineering

West Virginia University
Dept. of Industrial Engineering
and Institute of Occ. Safety
and Health

The Workplace Health Fund
Washington, DC

Yale University
School of Medicine
Occupational Medicine Program

Virginia Polytechnic Institute
and State University
Dept. of Industrial Engineering
and Operations Research

University of Kentucky
Preventive Medicine Medical
Center

Catonsville Community College
Catonsville, MD

Colorado State University
Occupat. Health and Safety
Dept.

University of Hawaii
School of Public Health

University of Iowa
Dept. of Preventive Medicine
and Environmental Health

University of South Florida
College of Public Health

Temple University
Ctr. for Environmental Studies

St. Augustine's College
Raleigh, NC

University of Puerto Rico
School of Public Health

San Diego State University
Grad. School of Public Health

University of South Carolina
Dept. of Environmental Health
Sciences

## AUPOSH
## EDUCATIONAL RESOURCE CENTERS

University of Alabama at
Birmingham
School of Public Health

University of Southern
California Institute of Safety
and Systems Management

University of Illinois at
Chicago Occupational Health and
Safety Center

The University of Michigan
Center for Occupational Health
and Safety Engr.

Mt. Sinai School of Medicine
New York/New Jersey E.R.C.

University of Texas (Houston)
Health Science Center
School of Public Health

University of Washington
Department of Environmental
Health

University of California at
Berkeley
School of Public Health

Harvard School of Public
Health

John Hopkins University
School of Hygiene and Public
Health

University of Minnesota
School of Public Health

University of North Carolina
North Carolina E.R.C.

University of Utah Medical
Center
Rocky Mountain Center for
Occupational Health

University of Cincinnati
Medical Center
Institute of Environmental
Health

# ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION

## STATEMENT OF THE NATIONAL COUNCIL ON ALCOHOLISM AND DRUG DEPENDENCE, INC.

The National Council on Alcoholism and Drug Dependence is the nation's oldest nonprofit health organization devoted to combating alcoholism, other drug addictions and related problems.

NCADD is vitally interested in the role the federal government plays in the research and prevention of alcohol related problems. We are also interested in maintaining the federal government's focus in these areas. NIDA and NIAAA are important components of the nation's commitment to reduce the toll of alcohol and other drug problems. The Alcohol, Drug Abuse and Mental Health Services (ADMS) block grant, the Office of Substance Abuse Prevention (OSAP) and the NIAAA Homeless Demonstration Projects funded under the Stewart B. McKinney Homeless Assistance Act are other key ingredients in our research, prevention and treatment efforts.

### NATIONAL INSTITUTE ON ALCOHOL ABUSE AND ALCOHOLISM

Despite the $120 billion annual cost to society, research into alcohol related problems has been minimal when compared to efforts put into federal research of other illnesses. In 1987, an estimated 105,095 Americans died from alcohol related cases--4.9% of the total national morbidity. Alcohol is also linked with nearly half of all assaults, rapes, and spouse and child abuse, and can cause liver cirrhosis, cancer and birth defects. We can not even begin to estimate the damage that is done by alcohol in terms of families that are torn apart and jobs that are lost.

NCADD encourages the Subcommittee to appropriate $189.7 million for NIAAA's research budget. This would allow for much needed new and continued research. This funding level will allow for the funding of 225 new and competing grants. At this funding level, we can ensure that important initiatives in the areas of prevention, genetics and treatment outcome research will receive adequate national attention. This will pave the way for major advances in our efforts to prevent, identify and treat alcoholism and related problems.

NCADD advocates $12.2 million for NIAAA AIDS related research. This research would focus on the relationship between alcohol use and high risk behavior and the role of problem drinking in spreading HIV infection. In addition, we support an appropriation of $6.2 million research training and $13.3 million in research management and program support.

We also strongly urge a $17.1 million appropriation for the homeless demonstration program housed in NIAAA. Vital demonstration programs which evaluate novel and comprehensive programs to homeless alcoholics, drug addicts and their families are currently underway in a number of communities across the country. We must sustain these programs and create funds for additional ones. Alcoholism and other drug addictions play an integral role in homelessness in America and the faces of the homeless have become more diverse over the last decade. It is imperative that funding be available for research and services to homeless women and their children, ethnic and racial minorities and those homeless persons who suffer from mental illness.

## NIDA

NCADD supports an appropriation of $332.2 million for research for NIDA. This funding level will allow for 328 new and competing grants. We also strongly advocate for adequate funding of NIDA's demonstration program at $133.5 million. This program funds treatment demonstrations for a number of critically under served populations. We can acquire enormous knowledge about treatment approaches while simultaneously providing desperately needed services to individuals in need.

## OFFICE FOR SUBSTANCE ABUSE PREVENTION

NCADD applauds the Office for Substance Abuse Prevention for its strong federal leadership in support of the prevention of alcohol and other drug problems. We are especially pleased with OSAP initiatives to increase resources to serve pregnant and post-partum women and their children; to target ethnic and racial minority youth; and to mobilize community-based prevention efforts. These efforts all show great promise and merit with continued and expanded federal support.

NCADD calls for a funding level of $220.3 million for OSAP demonstration programs, with a minimum of $50 million to be devoted to the program for pregnant and post-partum women and their infants. In addition, we support a funding level of $27.1 million for OSAP clinical training efforts and $15.6 million for prevention management and support.

## ALCOHOL, DRUG ABUSE AND MENTAL HEALTH SERVICES BLOCK GRANTS

NCADD requests an appropriations level of $1.6 billion for the ADMS block grant. Our inability as a nation to provide treatment to all Americans who seek recovery from alcoholism and other drug addiction undermines the credibility of the national war on drugs. Waiting lists for treatment remain common and must be reduced.

In addition, we must increase federal regulation of the ten percent set-aside of the block grant now earmarked for prevention and treatment services for alcoholic and drug dependent women.

Despite the presence of a federal requirement since 1984 that a portion of federal funds be devoted to women, the states' commitment to creating and expanding programs for women has been minimal. The proof of this minimal commitment has become markedly clear in light of numerous reports documenting the virtual absence of treatment programs which serve women and their children, generally, and pregnant women, specifically. Presumably, if states had complied with the spirit and the letter of federal law since 1984, we would not be currently experiencing the crisis in care for pregnant women and women with young children. Congress specifically identified the need for programs to serve these two populations of women in the 1984 legislation, and reitereated those priorities in 1986 and 1988. Strengthening the language accompanying the set-aside is urgently needed if the needs of alcoholic and other drug dependent women and their children are to be met.

We propose that the the Committee direct states to distribute women's set-aside funds through a centralized grant announcement process at the state level. Such a process will greatly facilitate the creation of tangible new and expanded services for women and their children and provide for greater state accountability to ADAMHA regarding the use of those federal funds.

The National Council on Alcoholism and Drug Dependence has been an historical leader in advocating for programs which respond to the special needs of women who are alcoholic and drug dependent. Last year, NCADD created a national Coalition on Alcohol and Drug Dependent Women and Their Children. This coalition is comprised of a group of national organizations concerned about the health and welfare of alcohol and drug dependent women and their families. Coalition members include organizations concerned about women's health care, legal issues, civil rights, child care alcohol and other drug problems, maternal and child health preventive and education services, prenatal care, and alcoholism and drug addiction treatment for women.

Over the last year, reports have proliferated about prosecutions of pregnant drug addicts and disputed the scarcity of treatment resources for them and their children. As the Committee deliberates about ADAMHA appropriations as well as those of other programs within the Department of Health and Human Services and Department of Education which might provide critical services for alcoholic and other drug dependent women and their children, we hope that you will ensure that adequate funding is available to help these families lead healthy and productive lives.

From our perspective, federal leadership and support for research, prevention, education and treatment is the heart and soul of an aggressive plan to reduce alcohol and other drug problems in the nation. Too often, these initiatives lumped under the rubric of demand reduction have taken a backseat in both financial support and rhetoric to drug enforcement and interdiction. Let us not lose sight of the primary public health and social dimensions of alcoholism and other drug addictions.

# STATEMENT OF THE RESEARCH SOCIETY ON ALCOHOLISM

The Research Society on Alcoholism, comprising the basic and clinical scientists of the United States working in the field of alcoholism and alcohol abuse research, propose for your serious consideration an alternative to the President's budget for Fiscal Year 1991 appropriations for the National Institute on Alcohol Abuse and Alcoholism.

On behalf of the Society, Mr. Chairman, I want to take this opportunity to express the gratitude of every member for the very important role you played in obtaining an additional $20 million for alcoholism research in connection with last year's Anti-Drug Initiative.

You have stated that, in Iowa, alcoholism and alcohol abuse are greater current problems than is drug abuse. It is a fact that alcoholism and alcohol abuse constitute major public health problems in America and impose a substantial public safety burden. These problems cost the nation's economy more than $116 billion annually, and yet the research needed to alleviate the economic and human costs amounts to approximately one-tenth of one percent of these costs.

The Research Society on Alcoholism knows that a number of areas of research have great potential for improving treatment and prevention modalities, thus ultimately reducing the terrible human and economic costs of alcoholism and abuse of alcohol. Among the most exciting avenues of research are the application of high technology imaging instruments to the actions of alcohol on the brain; the identification of genetic markers for determining susceptibility to alcoholism and alcohol abuse; and treatment modalities such as serotonin metabolism blockers and other new pharmacological agents which may alter alcohol consumption through better management of alcohol withdrawal and alleviation of craving.

In order to take advantage of current research knowledge and build upon it, the Research Society on Alcoholism urges the

Committee to approve an amount for NIAAA which in our collective professional judgement would be a prudent and effective level of expenditure.

We, therefore, urge an appropriation for Fiscal Year 1991 of $146.8 million for non-AIDS research and research training, $18.8 million for non-AIDS intramural research, and $12.8 million for non-AIDS research management and support, or a total of $178.4 million. In addition, we support the provision of $5 million for extramural facilities construction, and continuation of homeless demonstration projects.

The President's budget would provide level funding for NIAAA. Funding at the President's request level would result in severe and lasting damage to alcoholism research. The momentum created by the infusion of additional research dollars in Fiscal Year 1990 would be lost. More specifically, the President's budget contemplates an award rate for new and competing research project grants of only 20 percent. Put another way, only one in five approved grants could be funded, an eventuality that would seriously dampen new research initiatives.

One exciting research area is in the potential isolation of biologic markers of alcohol consumption. The development of such markers would be a major contribution to the alcoholism field, and would permit early detection of alcohol induced disease and early referral to alcoholism treatment. Objective markers would also provide alcoholism treatment professionals with a tool to assess treatment compliance by monitoring actual, rather than self-reported, drinking behavior.

Recently evolving research on a brain neurotransmitter system may be critically important to phenomena of alcohol intoxication, tolerance, dependence, and the memory impairments induced by alcohol use. Advanced technology imaging techniques, using Position Emission Tomography, magnetoencephalography and other devices have yet to be vigorously applied to study the actions of alcohol on the brain. Additional research projects would permit such research applications including the exploration of the actions of alcohol in specific brain structures and sites, as well as study of the processes by which alcohol can elicit specific organic brain disease.

In 1989, with funding generated by this Committee, a cooperative genetics research program was launched by NIAAA. This multisite, multidisciplinary project is designed to identify genes which contribute to the development of alcoholism in at-risk individuals. The cooperative effort will focus on individuals drawn from families at higher risk for the development of the disease. This is a major long-term project of great potential significance in the study of genetic etiologies in alcoholism and needs this committee's continued full support.

Even with the additional infusion of funds for NIAAA in Fiscal Year 1990, research training stipends did not increase. We strongly support funding for 79 additional research trainees. There are currently critical shortages of alcohol investigators in a number of key disciplinary areas. Such shortages relate to research in the treatment of alcoholism, study of the organic brain disease and neuropathies derived from alcoholism, study of alcoholic liver disease, alcoholic pancreatic disease, alcohol-derived diseases of the heart and circulatory system, clinical study of fetal alcohol syndrome and other alcohol-related birth defects, and the study of the impact of alcohol on the childhood and adolescent development processes.

There is also critical need to train basic scientists to address the increasing number of questions emerging from the current excitement and interest in many alcohol-related issues. These scientists would approach research questions which range from the interaction of alcohol with specific neurotransmitter systems to the actions of alcohol in altering cell member function, to the study of the effects on peer interactions and family functioning. Because alcohol research is not in and of itself a unique discipline, but rather requires scientists from many diverse disciplines, the research training afforded through the NRSA program of NIAAA provides the specialized training essential to enter into active research in this area.

There is a great need to combine the research efforts of behavioral scientists and basic biomedical investigators in a team approach. It is now clear to the research scientists in the field that alcoholism and alcohol abuse are not entirely behavioral and environmental, nor entirely biological. If we are to fully and appropriately address the diseases and conditions of alcoholism and alcohol abuse, we must investigate the underlying etiologies through multidisciplinary approaches.

Attached to this statement is a table which provides in detail the recommendations of the Research Society on Alcoholism for Fiscal Year 1991, and which compares the recommendations with the President's budget and funds appropriated for Fiscal Year 1990. We will be pleased to serve as a resource to this Committee, and to answer any questions it may have regarding funding for the National Institute on Alcohol Abuse and Alcoholism.

The Research Society on Alcoholism appreciates this Committee's support for NIAAA research and urges it to adopt our recommendations for Fiscal Year 1991.

NIAAA Research and Research Training
Funding Recommendations for FY 1991
(Non-AIDS*)
(In Millions of Dollars)

| | FY 1990 Approp. | President's FY 1991 | RSA Rec. FY 1991 |
|---|---|---|---|
| Res. Project Grants | 76.5 | 80.0 | 106.2 |
| Centers | 17.0 | 17.8 | 18.9 |
| Other research | 8.5 | 8.4 | 10.2 |
| R&D contracts | 5.2 | 5.2 | 5.7 |
| Subtotal, Extramural Res. | 107.2 | 111.4 | 141.0 |
| Res. Training | 2.8 | 3.0 | 5.8 |
| Intramural Res. | 17.0 | 17.9 | 18.8 |
| Res. Mgt. & Support | 10.6 | 11.7 | 12.8 |
| TOTAL Res./Res. Training | $137.6 | $144.0 | $178.4 |

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*AIDS Research: FY 1990 appropriated - $8.2
FY 1991 budget - $9.2

# STATEMENT OF THE NATIONAL ASSOCIATION OF STATE ALCOHOL AND DRUG ABUSE DIRECTORS

MR. CHAIRMAN AND MEMBERS OF THE SUBCOMMITTEE. THANK YOU FOR THE OPPORTUNITY TO SUBMIT COMMENTS ON THE PRESIDENT'S FISCAL YEAR 1991 BUDGET REQUEST FOR FEDERAL ALCOHOL AND OTHER DRUG ABUSE PROGRAMS.

MY NAME IS JOHN GUSTAFSON. I AM DEPUTY DIRECTOR WITH THE DIVISION OF SUBSTANCE ABUSE SERVICES FOR THE STATE OF NEW YORK AND CURRENTLY SERVE AS PRESIDENT OF THE NATIONAL ASSOCIATION OF STATE ALCOHOL AND DRUG ABUSE DIRECTORS (NASADAD). NASADAD IS A NOT-FOR-PROFIT ORGANIZATION WHOSE MEMBERSHIP IS COMPRISED EXCLUSIVELY OF THE STATE AND TERRITORIAL OFFICIALS DESIGNATED BY THE GOVERNORS TO ADMINISTER THE PUBLICLY FUNDED ALCOHOL AND DRUG ABUSE TREATMENT AND PREVENTION SYSTEM.

## CONTINUING NEED FOR ADDITIONAL FEDERAL RESOURCES FOR THE ALCOHOL, DRUG ABUSE AND MENTAL HEALTH BLOCK GRANT

ACROSS OUR NATION ALCOHOL AND OTHER DRUG ABUSE PROBLEMS CONTINUE TO GROW IN MAGNITUDE AND SEVERITY, PARTICULARLY AMONG OUR YOUTH. STATES AND LOCAL COMMUNITIES THROUGHOUT THE COUNTRY HAVE A SIGNIFICANT AND GROWING NEED FOR ADDITIONAL FEDERAL RESOURCES FOR ALCOHOL AND OTHER DRUG ABUSE PREVENTION, INTERVENTION AND TREATMENT SERVICES. TREATMENT CAPACITY MUST BE EXPANDED, ADDITIONAL ACTIVITIES TO REDUCE THE AIDS/HIV CRISIS MUST BE UNDERTAKEN AND NEW PREVENTION, INTERVENTION AND TREATMENT ACTIVITIES TARGETING SPECIAL POPULATIONS MUST BE INITIATED.

EXAMPLES OF THE CONTINUING NEED FOR ALCOHOL AND OTHER DRUG TREATMENT SERVICES INCLUDE THE FOLLOWING:

- IN A RECENT SURVEY ON WAITING LISTS, STATES REPORTED THAT ALMOST 67,000 PERSONS WERE CURRENTLY LISTED ON TREATMENT WAITING LISTS;
- APPROXIMATELY ONE HALF OF THOSE ON WAITING LISTS HAD BEEN WAITING FOR TREATMENT FOR AT LEAST 30 DAYS;

- THE REPORTING STATES INDICATED THAT APPROXIMATELY 1,407,519 PERSONS PER YEAR ARE CURRENTLY RECEIVING ALCOHOL AND OTHER DRUG ABUSE TREATMENT, INCLUDING 1,283,994 ADULTS AND 123,525 ADOLESCENTS;
- THE STATES ALSO ESTIMATED THAT THE TOTAL NUMBER OF ADDITIONAL PERSONS NEEDING ALCOHOL AND OTHER DRUG ABUSE TREATMENT IS 10,596,479, INCLUDING 8,973,483 ADULTS AND 1,601,996 ADOLESCENTS.
- IN FY 1988, STATES ESTIMATED THAT THERE WERE A TOTAL OF 1.3 MILLION INTRAVENOUS DRUG ABUSERS (IVDUS) IN THE U.S.; ONLY 162,929 IVDUS WERE ADMITTED TO PUBLICLY FUNDED TREATMENT PROGRAMS - ABOUT 10 PERCENT OF THOSE NEEDING TREATMENT.

THE PUBLICLY FUNDED ALCOHOL AND OTHER DRUG ABUSE PREVENTION AND TREATMENT NETWORK RELIES ON FINANCIAL SUPPORT FROM ALL LEVELS OF GOVERNMENT - FEDERAL, STATE AND LOCAL. THIS PARTNERSHIP HAS EVOLVED OVER THE PAST TWO DECADES WITH THE ROLES AND RESPONSIBILITIES OF THE VARIOUS GOVERNMENTAL ENTITIES CHANGING OVER THE YEARS.

SINCE 1981, THE ALCOHOL, DRUG ABUSE AND MENTAL HEALTH SERVICES (ADMS) BLOCK GRANT HAS BEEN THE PRIMARY FEDERAL FUNDING MECHANISM FOR ALCOHOL AND OTHER DRUG ABUSE PREVENTION AND TREATMENT SERVICES AND FOR COMMUNITY MENTAL HEALTH SERVICES. THE ADMS BLOCK GRANT REMAINS THE MOST VIABLE MANNER TO EQUITABLY DISTRIBUTE FEDERAL SERVICE DOLLARS TO ENSURE THE SYSTEMATIC, COORDINATED DELIVERY OF SERVICES TO ALL STATES AND LOCAL COMMUNITIES. THE CREATION OF CATEGORICAL FUNDING MECHANISMS INHIBITS OVERALL STATE PLANNING AND COORDINATION, AND ALSO CAUSES DELAYS IN THE USE OF FEDERAL FUNDS.

RECENTLY, THE STATE ALCOHOL AND DRUG ABUSE AGENCIES WERE ASKED TO PROVIDE INFORMATION ON THE USE OF FY 1989 FEDERAL AND STATE FUNDS FOR ALCOHOL AND OTHER DRUG ABUSE TREATMENT, INCLUDING SERVICES IN RURAL AND URBAN AREAS AND SERVICES TO WOMEN. ADDITIONALLY, STATES PROVIDED EXAMPLES OF PROGRAMS

OFFERING TREATMENT SERVICES TO WOMEN, INCLUDING PREGNANT WOMEN AND PROGRAMS SERVING PERSONS WITH AIDS/HIV.

FORTY-THREE STATES, THE DISTRICT OF COLUMBIA, PUERTO RICO AND THE VIRGIN ISLANDS RESPONDED TO THE SURVEY AND REPORTED THAT THE STATES' TOTAL AMOUNT OF FY 1989 ADMS BLOCK GRANT FUNDS FOR ALCOHOL AND OTHER DRUG ABUSE PREVENTION, INTERVENTION AND TREATMENT SERVICES WAS $468 MILLION. OTHER FUNDS TOTALED $1.43 BILLION, BRINGING THE TOTAL AMOUNT OF FUNDS TO $1.9 BILLION.

OF THE TOTAL FUNDING, THE STATES REPORTED THAT OVER $349 MILLION, ALMOST 20 PERCENT, WAS SPECIFICALLY EARMARKED FOR ALCOHOL AND OTHER DRUG ABUSE TREATMENT SERVICES TO WOMEN. IN ADDITION, WOMEN ARE SERVED ALONG WITH MEN IN MOST TREATMENT PROGRAMS. REGARDING TREATMENT AND PREVENTION SERVICES IN RURAL AND URBAN AREAS, THE REPORTING STATES INDICATED THAT APPROXIMATELY $1 BILLION OF THE TOTAL FUNDING WAS ALLOCATED TO LARGE URBAN AREAS, $314 MILLION TO MEDIUM-SIZED POPULATION AREAS AND $312 MILLION TO RURAL AREAS.

## FY 1991 APPROPRIATIONS RECOMMENDATION

THE ADMINISTRATION'S FY 1991 BUDGET REQUEST OF A $100 MILLION INCREASE FOR THE DRUG PORTION ONLY OF THE ADMS BLOCK GRANT IS NOT ADEQUATE.

IN ADDITION, NASADAD MEMBERS OBJECT TO THE DESIGNATION OF A FUNDING INCREASE FOR DRUG ABUSE TREATMENT ONLY. ALCOHOL CONTINUES TO BE OUR NATION'S NUMBER ONE DRUG OF ABUSE AND THE PROBLEMS ASSOCIATED WITH ALCOHOL ALONE OR IN COMBINATION WITH OTHER DRUGS ARE OF DRAMATIC PROPORTIONS. THE NATIONAL INSTITUTE ON ALCOHOL ABUSE AND ALCOHOLISM'S 7TH REPORT TO CONGRESS INDICATES THAT AN ESTIMATED 10.5 MILLION U.S. ADULTS EXHIBIT SYMPTOMS OF ALCOHOLISM OR ALCOHOL DEPENDENCE AND AN ADDITIONAL 7.2 MILLION ABUSE ALCOHOL. ADDITIONALLY, IT IS ESTIMATED THAT 4.5 MILLION ADOLESCENTS ARE DEPENDENT ON ALCOHOL, OR ARE PROBLEM DRINKERS. OUR COUNTRY'S SO-CALLED "WAR ON DRUGS" MUST NOT FOCUS SOLELY ON ILLICIT SUBSTANCES.

NEXT, THE ADMINISTRATION'S FY 1991 BUDGET REQUEST DOES NOT PROVIDE SUFFICIENT FEDERAL FUNDING TO MEET THE GOALS OF THE NATIONAL DRUG CONTROL STRATEGY AND THE PRIORITIES ARTICULATED BY CONGRESS. THE NATIONAL DRUG CONTROL STRATEGY HAS IDENTIFIED A NUMBER OF PRIORITIES THAT PLACE ADDITIONAL RESPONSIBILITIES ON THE STATES, INCLUDING THE SUBMISSION OF STATE PLANS FOR TREATMENT RESOURCE ALLOCATION AND SYSTEMIC IMPROVEMENTS; IMPROVED COORDINATION AMONG LOCAL TREATMENT PROVIDERS AND BETWEEN TREATMENT PROVIDERS AND OTHER HEALTH AND SOCIAL SERVICE PROVIDERS; INCREASED FUNDING FOR OUTREACH AND TREATMENT PROGRAMS FOR PREGNANT WOMEN; AND EXPANDED AND IMPROVED DATA COLLECTION AND EVALUATION. ADDITIONALLY, BOTH THE ADMINISTRATION AND THE CONGRESS RECOGNIZE THE NEED TO PROVIDE MORE CASE MANAGEMENT AND COMMUNITY-BASED TREATMENT SERVICES TO ALCOHOL AND DRUG DEPENDENT OFFENDERS TO BREAK THE LINK BETWEEN SUBSTANCE ABUSE AND CRIME.

WHILE THE STATES WOULD AGREE THAT EACH OF THESE AREAS HAS MERIT AND SHOULD BE FOCUSED ON, IT WILL BE DIFFICULT TO MEET THESE PRIORITIES, AS WELL AS THE CALL FOR ADDITIONAL TREATMENT SLOTS, WITH THE AMOUNT OF FEDERAL FUNDS BEING REQUESTED BY THE PRESIDENT.

DUE TO THE ESCALATING UNMET TREATMENT NEEDS OF ALCOHOL AND OTHER DRUG ABUSERS IN ALL AREAS OF THE COUNTRY - URBAN AND RURAL, INCLUDING THE ALARMING INCREASE OF AIDS AMONG IV DRUG ABUSERS AND THE GROWING CRACK/COCAINE EPIDEMIC, NASADAD RESPECTFULLY REQUESTS THAT THE MEMBERS OF THE APPROPRIATIONS SUBCOMMITTEE SERIOUSLY CONSIDER APPROPRIATING A MUCH HIGHER AMOUNT FOR THE ADMS BLOCK GRANT. SPECIFICALLY, WE RECOMMEND THAT $3 BILLION BE APPROPRIATED FOR FY 1990. THIS MAGNITUDE OF INCREASE WOULD BEGIN TO ADDRESS THE REAL NEEDS FOR TREATMENT AND PREVENTION AMONG OUR NATION'S CITIZENS.

## Survey on State Alcohol and Drug Agency Use of FY 1989 Federal and State Funds

Highlights of Results from Recent NASADAD Survey on State Alcohol and Drug Agency Use of FY 1989 Federal and State Funds.

Tables

1. Total Amount of State FY 1989 Block Grant and Other Funds.
2. Percent and Amount of Total State Funding for Treatment Services for Women.
3. Approximate Number of Women Per Year, Including Pregnant Women, Currently Receiving Treatment Compared to the Total Number of Women Needing Treatment.
4. Proportion of Total Funding Allocated for Treatment Prevention Services in Urban, Medium, and Rural Areas.
5. Proportion of Total Funding for Treatment Services in Cities over 250,000, Populations 50-250,000, and Rural Areas Less than 50,000.
6. Total Funding for Treatment and Prevention Services for Urban, Medium, and Rural Areas.

Appendices

I. Examples of Special Treatment Intervention or Prevention Programs for Pregnant Women-on a State by State Basis.

II. Examples of Special Treatment, Intervention or Prevention Programs for AIDS/HIV Infected or At-Risk Persons-on a State by State Basis.

## Highlights of Results from Recent NASADAD Survey on State Alcohol and Drug Agency Use of FY 1989 Federal and State Funds

- Forty-three States, the District of Columbia, Puerto Rico, and the Virgin Islands responded to the survey and reported that the total amount of FY 89 Block Grant was $468 million. Other funds totaled $1.431 billion and total block grant and other funds were $1.9 billion. (Table 1)
- The total amount of funding for treatment services for women was over $349 million, almost 20% of the total funding for all treatment services. (Table 2)
- The approximate total number of women per year, including pregnant women, who are currently receiving treatment is 548,326 with the total number of pregnant women being 29,842 (Table 3)
- The approximate total number of women needing treatment is 4,004,803 and the number of pregnant women needing treatment is 250,362 (Table 3)
- The proportion of total funding allocated for treatment and prevention services per State in large urban areas, medium population areas, and in rural areas is shown in table 4.
- The proportion of total funding for treatment services per State for cities over 250,000, for populations 50 to 250,000, and in rural areas less than 50,000 is shown in table 5.
- The reporting States indicated that approximately $1 billion of total funding was allocated to large urban areas, $314 million to medium population areas and $312 million to rural areas. (Table 6)

See Appendix I for examples of special treatment, intervention and prevention programs for pregnant women.

See Appendix II for examples of special treatment, intervention and prevention programs for AIDS/HIV-infected or at-risk persons.

## TABLE 1

## SURVEY OF STATE ALCOHOL AND DRUG AGENCY USE OF FY 1989 FEDERAL AND STATE FUNDS
($ in Millions)

| STATE | Amount of FY 89 Block Grant | FY 89 Other Funds | Total |
|---|---|---|---|
| Alabama | $ 2,553,618 | $ 5,949,537 | $ 8,503,155 |
| Alaska | 2,542,300 | 14,843,300 | 17,385,600 |
| Arizona | 6,904,090 | 20,696,069 | 27,600,159 |
| Arkansas | 3,406,310 | 2,817,756 | 6,224,066 |
| California | 91,700,000 | 240,600,000 | 332,300,000 |
| Colorado | 7,659,190 | 12,793,651 | 20,452,841 |
| Connecticut | 7,339,332 | 42,758,725 | 50,098,057 |
| Delaware | 2,005,300 | 3,158,400 | 5,163,700 |
| District of Columbia | 2,815,850 | 30,852,053 | 33,667,908 |
| Florida | 33,330,850 | 34,742,368 | 68,073,218 |
| Georgia | 9,600,765 | 34,893,174 | 44,493,933 |
| Idaho | 1,325,987 | 1,552,716 | 2,878,703 |
| Illinois | 18,360,282 | 58,371,792 | 76,732,074 |
| Indiana | 6,790,091 | 8,138,938 | 14,929,029 |
| Iowa | 4,809,000 | 7,635,007 | 12,444,007 |
| Kansas | 3,541,977 | 4,543,358 | 8,085,335 |
| Kentucky | 4,893,895 | 8,712,428 | 13,606,323 |
| Louisiana | 7,714,418 | 3,821,685 | 11,536,103 |
| Maine | 2,600,000 | 5,400,000 | 8,000,000 |
| Maryland | 7,023,700 | 50,444,400 | 57,468,100 |
| Massachusetts | 14,844,350 | 45,218,433 | 60,062,783 |
| Michigan | 21,820,386 | 32,149,080 | 53,969,466 |
| Minnesota | 7,694,000 | 39,943,000 | 47,637,000 |
| Mississippi | 3,426,500 | 5,356,462 | 8,782,962 |
| Missouri | 8,508,000 | 11,752,000 | 20,260,000 |
| Montana | 1,455,727 | 1,490,598 | 2,946,325 |
| Nebraska | 2,597,903 | 6,058,226 | 8,656,129 |
| Nevada | 2,567,789 | 3,506,871 | 6,074,660 |
| New Hampshire | 1,980,818 | 2,190,049 | 4,170,867 |
| New Jersey | 19,445,000 | 39,398,000 | 58,843,000 |
| New York (ALC) | 16,615,000 | 76,258,263 | 92,873,263 |
| New York (DRUG) | 33,761,000 | 282,652,440 | 316,413,440 |
| North Carolina | 10,168,597 | 17,160,544 | 27,329,141 |
| North Dakota | 1,366,103 | 1,898,074 | 3,264,177 |
| Ohio | 18,436,281 | 16,416,104 | 34,852,385 |
| Oregon | 8,111,000 | 8,600,000 | 16,711,000 |
| Puerto Rico | 6,695,280 | 23,824,886 | 30,520,166 |
| South Carolina | 4,745,746 | 9,967,746 | 14,713,492 |
| Tennessee | 6,056,642 | 7,752,480 | 13,809,122 |
| Texas | 11,585,741 | 41,145,249 | 52,730,990 |
| Utah | 3,972,113 | 5,788,800 | 9,760,913 |
| Vermont | 1,907,282 | 2,812,911 | 4,720,193 |
| Virgin Islands | 423,330 | 826,505 | 1,249,835 |
| Virginia | 10,971,705 | 38,460,510 | 49,432,215 |
| Washington | 9,331,000 | 41,600,000 | 51,931,000 |
| West Virginia | 3,475,000 | 4,163,000 | 7,638,000 |
| Wisconsin | 9,949,600 | 72,801,897 | 82,751,497 |
| **TOTAL** | **$468,828,848** | **$1,431,917,485** | **$1,900,746,333** |

## TABLE 2

## PERCENT AND AMOUNT OF TOTAL FUNDING FOR TREATMENT SERVICES FOR WOMEN

| STATE | Percent | Amount | |
|---|---|---|---|
| Alabama | 16.9% | $ 1,434,748 | |
| Alaska | 26 | 3,153,800 | |
| Arizona | 4 | 1,020,539 | |
| Arkansas | 25.6 | 1,593,361 | |
| California | 29.3 | 66,700,000 | |
| Colorado | 10.3 | 2,107,318 | |
| Connecticut | 13 | 932,984 | |
| Delaware | 20 | 1,013,200 | |
| District of Columbia | 33 | 11,000,000 | |
| Florida | 10 | 3,333,085 | |
| Georgia | 10 | N/A | |
| Idaho | 27 | 777,250 | |
| Illinois | 5.6 | 3,137,785 | dedicated women's svs |
| | 23.1 | 12,325,031 | women served in community based system |
| Indiana | 19.1 | 2,976,236 | |
| Iowa | 4.5 | 445,285 | |
| Kansas | 6.3 | 511,652 | |
| Kentucky | 22.7 | 2,503,806 | |
| Louisiana | 30 | 2,368,220 | |
| Maine | 9.2 | 737,443 | |
| Maryland | 10 | 5,700,000 | |
| Massachusetts | 23 | 13,110,000 | |
| Minnesota | 30 | 14,291,000 | |
| Mississippi | 21 | 1,844,422 | |
| Missouri | 28 | 3,774,125 | |
| Montana | 39 | 958,507 | |
| Nebraska | 21.7 | 1,878,709 | |
| Nevada | 27 | 1,638,214 | |
| New Hampshire | 26 | 563,261 | |
| New Jersey | 20 | 11,890,000 | |
| New York (Alcohol) | 18.6 | 4,335,213 | |
| New York (Drug) | 41 | 101,572,249 | |
| North Carolina | 3.2 | 874,323 | |
| North Dakota | 30 | 975,000 | |
| Ohio | 10 | 3,656,000 | |
| Oregon | 29 | 3,215,013 | |
| Puerto Rico | 12.1 | 3,697,382 | |
| South Carolina | 16 | 1,579,908 | |
| Tennessee | 25 | 3,700,000 | |
| Texas | 23.9 | 6,590,526 | |
| Utah | 10 | 390,000 | |
| Vermont | 27 | 852,000 | |
| Virginia | 26.7 | 11,976,890 | |
| Washington | 33.5 | 16,844,000 | |
| West Virginia | 7.5 | 571,000 | |
| Wisconsin | 24.4 | 15,006,840 | |
| **TOTAL** | | **$349,556,325** | |

## TABLE 3

## APPROXIMATE NUMBER OF WOMEN PER YEAR, INCLUDING PREGNANT WOMEN, CURRENTLY RECEIVING TREATMENT COMPARED TO THE TOTAL NEEDING TREATMENT

| STATE | Number of Women Receiving Treatment | | Number of Women Needing Treatment | |
|---|---|---|---|---|
| | Total | Pregnant | Total | Pregnant |
| Alabama | 3,821 | 2,100 | 5,900 | 3,900 |
| Alaska | 2,383 | 167 | 11,915 | 834 |
| Arizona | 8,371 | 476 | 30,168 | 1,716 |
| Arkansas | 2,265 | 100 | 118,174 | 4,727 |
| California | 50,900 | 2,500 | 3,000 | 200 |
| Colorado | 11,089 | 125 | 101,000 | N/A |
| Connecticut | 7,224 | 23 | N/A | N/A |
| Delaware | 1,385 | 21 | N/A | N/A |
| District of Columbia | 1,900 | 511 | 19,000 | 1,800 |
| Florida | 7,446 | 1,500 | 45,396 | 10,000 |
| Georgia | 12,810 | 250 | 250,000 | 10,000 |
| Idaho | 1,881 | N/A | 50,599 | N/A |
| Illinois | 20,933 | 5,810 | 53,200 | 17,592 |
| Indiana | 15,000 | 225 | 200,000 | 2,160 |
| Iowa | 8,102 | N/A | 81,020 | N/A |
| Kansas | 8,276 | 23 | 120,673 | 360 |
| Kentucky | 4,139 | 40 | 56,800 | 2,552 |
| Louisiana | 6,126 | 210 | 65,000 | 7,112 |
| Maine | 3,000 | 90 | 49,000 | 4,410 |
| Maryland | 15,000 | 900 | 100,000 | 5,700 |
| Massachusetts | 23,000 | 200 | 150,000 | 5,000 |
| Michigan | 32,528 | 2,765 | 300,000 | 25,500 |
| Minnesota | 12,000 | 1,200 | 100,000 | 6,000 |
| Mississippi | 2,423 | 363 | N/A | N/A |
| Missouri | 6,372 | 93 | 68,819 | 4,396 |
| Montana | 1,694 | 17 | 34,000 | 340 |
| Nebraska | 5,289 | 343 | 29,280 | 1,918 |
| Nevada | 2,282 | 50 | 10,000 | 500 |
| New Hampshire | 3,633 | 200+/- | 26,900 | 1,630 |
| New Jersey | 17,500 | 875 | 125,000 | 6,000 |
| New York (Alcohol) | 34,828 | N/A | 416,780 | N/A |
| New York (Drug) | 25,948 | 800 | 279,000 | 24,000 |
| North Carolina | 10,636 | 1,250 | 31,908 | 3,800 |
| North Dakota | 700 | N/A | N/A | N/A |
| Ohio | 4,447 | N/A | N/A | N/A |
| Oregon | 8,306 | N/A | N/A | N/A |
| Puerto Rico | 99,775 | 3,625 | 680,637 | 75,000 |
| South Carolina | 7,498 | 633 | 75,646 | 6,385 |
| Tennessee | 3,857 | 5 | 30,000 | 30 |
| Texas | 6,530 | N/A | 37,622 | N/A |
| Utah | 2,749 | 100 | 30,000 | 1,200 |
| Vermont | 1,500 | 150 | 6,700 | 600 |
| Virgin Islands | 9 | 2 | N/A | N/A |
| Virginia | 16,796 | 1,200 | 150,000 | 12,500 |
| Washington | N/A | 900 | 61,666 | 2,500 |
| West Virginia | 2,283 | N/A | N/A | N/A |
| Wisconsin | 23,692 | N/A | N/A | N/A |
| TOTAL | 548,326 | 29,842 | 4,004,803 | 250,362 |

## TABLE 4

## PROPORTION OF TOTAL FUNDING ALLOCATED FOR TREATMENT PREVENTION SERVICES (PERCENT)

| STATE | Large Urban Areas | Medium Population Areas | Rural Areas |
|---|---|---|---|
| Alaska | 0 | 39 | 61 |
| Arizona | 54 | 22 | 24 |
| Arkansas | 28 | 0 | 72 |
| California | 87 | 10 | 3 |
| Colorado | 60.8 | 24.4 | 14.7 |
| Connecticut | 60 | 28 | 12 |
| District of Columbia | 100 | 0 | 0 |
| Georgia | 32 | 39 | 29 |
| Florida | 60 | 30 | 10 |
| Idaho | 0 | 22.1 | 77.9 |
| Illinois | 55.4 | 8.1 | 36.5 |
| Indiana | 39.1 | 51.5 | 9.4 |
| Iowa | 10 | 37 | 53 |
| Kansas | 71 | 0 | 29 |
| Kentucky | 34.5 | 39.3 | 26 |
| Louisiana | 48 | 25 | 16 |
| Maine | 0 | 22 | 78 |
| Maryland | 46 | 12 | 41 |
| Massachusetts | 29 | 47 | 24 |
| Michigan | 30.9 | 40.2 | 15.3 |
| Minnesota | 50 | 25 | 25 |
| Mississippi | 14 | 0 | 86 |
| Missouri | 37.6 | 11.8 | 50.6 |
| Montana | 8 | 21 | 71 |
| Nebraska | 36.3 | 32.8 | 30.9 |
| Nevada | 55 | 25 | 20 |
| New Jersey | 10 | 36 | 54 |
| New York (Alcohol) | 74.2 | 19.5 | 3.8 |
| New York (Drug) | 93.5 | 2 | 4.5 |
| North Carolina | 0 | 24 | 76 |
| North Dakota | 0 | 20 | 80 |
| Ohio | 60 | 25 | 15 |
| Oregon | 58 | 18 | 24 |
| Puerto Rico | 18.6 | 18.9 | 9.7 |
| South Carolina | 38 | 46 | 16 |
| Tennessee | 40 | 28 | 32 |
| Texas | 68 | 26 | 6 |
| Utah | 57 | 35 | 8 |
| Vermont | 0 | 19.5 | 80.5 |
| Virginia | 48 | 19 | 33 |
| Washington | 59.6 | 23.3 | 17.1 |
| West Virginia | 0 | 12 | 88 |
| Wisconsin | 42.9 | 38.1 | 19 |

## TABLE 5

## PROPORTION OF TOTAL FUNDING FOR TREATMENT SERVICES (PERCENT)

| STATE | Cities Over 250,000 | Populations 50-250,000 | Rural Areas Less Than 50,000 |
|---|---|---|---|
| Alaska | 0 | 41 | 59 |
| Arizona | 54 | 22 | 24 |
| Arkansas | 28 | 6 | 66 |
| California | 87 | 10 | 3 |
| Colorado | 60.7 | 24.4 | 14.9 |
| Connecticut | 63 | 26 | 11 |
| District of Columbia | 100 | 0 | 0 |
| Florida | 40 | 50 | 10 |
| Georgia | 38 | 62 | N/A |
| Idaho | 0 | 100 | 0 |
| Illinois | 46.1 | 22.6 | 31.3 |
| Indiana | 38.4 | 51.6 | 10 |
| Iowa | 10 | 34 | 56 |
| Kansas | 34 | 36 | 30 |
| Kentucky | 24.3 | 75.7 | 0 |
| Louisiana | 54 | 28 | 18 |
| Maine | 0 | 24 | 76 |
| Massachusetts | 31 | 48 | 21 |
| Michigan | 25.8 | 29.3 | 10.3 |
| Minnesota | 50 | 25 | 25 |
| Mississippi | 13 | 0 | 87 |
| Missouri | 37.6 | 11.8 | 50.6 |
| Montana | 0 | 29 | 71 |
| Nebraska | 37.2 | 32.7 | 30.1 |
| Nevada | 55 | 25 | 20 |
| New Hampshire | 0 | 50+/- | 50+/- |
| New Jersey | 12 | 42 | 46 |
| New York (Alcohol) | 78.2 | 18.9 | 3 |
| New York (Drug) | 78 | 4 | 18 |
| North Carolina | 23 | 77 | 0 |
| North Dakota | 0 | 20 | 80 |
| Oregon | 35 | 15 | 50 |
| Puerto Rico | 16.7 | 8.5 | 3.7 |
| South Carolina | 31 | 29 | 9 |
| Tennessee | 40 | 28 | 32 |
| Texas | 70 | 25 | 5 |
| Utah | 57 | 35 | 8 |
| Vermont | 0 | 19.5 | 80.5 |
| Virginia | 48 | 19 | 33 |
| West Virginia | 0 | 11 | 89 |
| Wisconsin | 36.5 | 44.5 | 19 |

## TABLE 6
## TOTAL FUNDING FOR TREATMENT AND PREVENTION SERVICES

| STATE | URBAN | MEDIUM | RURAL |
|---|---|---|---|
| Alaska | $ 0 | $6,780,384 | $10,605,216 |
| Arizona | 14,904,086 | 6,072,035 | 6,624,038 |
| Arkansas | 1,742,738 | 0 | 4,481,328 |
| California | 289,101,000 | 33,230,000 | 9,969,000 |
| Colorado | 12,435,327 | 4,990,493 | 3,006,568* |
| Connecticut | 30,058,834 | 14,027,456 | 6,011,767 |
| District of Columbia | 33,667,908 | 0 | 0 |
| Florida | 40,843,931 | 20,421,965 | 6,807,322 |
| Idaho | 0 | 636,193 | 2,242,510 |
| Illinois | 42,509,569 | 6,215,298 | 28,007,207 |
| Indiana | 5,837,250 | 7,688,450 | 1,403,329 |
| Iowa | 1,244,401 | 4,604,287 | 6,595,324 |
| Kansas | 5,740,588 | 0 | 2,344,747 |
| Kentucky | 4,694,181 | 5,347,285 | 3,537,644* |
| Louisiana | 5,537,329 | 2,884,026 | 1,845,776* |
| Maine | 0 | 1,760,000 | 6,240,000 |
| Maryland | 25,144,585 | 6,547,332 | 22,286,350 |
| Massachusetts | 17,418,207 | 28,229,508 | 14,415,068 |
| Michigan | 16,676,565 | 21,695,725 | 8,257,328* |
| Minnesota | 23,818,500 | 11,909,250 | 11,909,250 |
| Mississippi | 1,229,615 | 0 | 7,553,347 |
| Missouri | 7,617,760 | 2,390,680 | 10,251,560 |
| Montana | 235,706 | 618,728 | 2,091,891 |
| Nebraska | 3,142,175 | 2,839,210 | 2,674,744 |
| Nevada | 3,341,063 | 1,518,665 | 1,214,932 |
| New Jersey | 5,884,300 | 21,183,480 | 31,775,220 |
| New York (Alcohol) | 68,911,961 | 18,110,286 | 3,529,184 |
| New York (Drug) | 295,846,566 | 6,328,269 | 14,238,605 |
| North Carolina | 0 | 6,558,994 | 20,770,147 |
| North Dakota | 0 | 652,835 | 2,611,342 |
| Ohio | 20,911,431 | 8,717,096 | 5,227,858 |
| Oregon | 9,692,380 | 3,007,980 | 4,010,640 |
| Puerto Rico | 5,676,751 | 5,768,311 | 2,960,456* |
| South Carolina | 5,591,127 | 6,768,206 | 2,354,159 |
| Tennessee | 5,523,649 | 3,866,554 | 4,418,919 |
| Texas | 35,857,073 | 17,710,057 | 3,163,860 |
| Utah | 5,563,720 | 3,416,320 | 780,873 |
| Vermont | 0 | 920,438 | 3,799,755 |
| Virginia | 23,727,463 | 9,392,121 | 16,312,631 |
| Washington | 30,950,876 | 12,099,923 | 8,880,201 |
| West Virginia | 0 | 916,560 | 6,721,440 |
| TOTAL | 1,075,934,030 | 315,887,400 | 311,931,536 |

*Does not reflect total Federal and State funds

## APPENDIX I

### EXAMPLES OF SPECIAL TREATMENT INTERVENTION OR PREVENTION PROGRAMS FOR PREGNANT WOMEN ON A STATE-BY-STATE BASIS

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| **ALASKA** | | | |
| Reflections/Anchorage | $420,537 | Residential w/childcare | 129 |
| New Dawn/Anchorage | $136,120 | Residential w/childcare | 43 |
| **ARKANSAS** | | | |
| Arkansas High risk<br>Pregnancy Program<br>UAMS Dept. OB-GYN<br>4301 W. Markham<br>Little Rock, AR<br>Cynthia Crone, CPNP,BSN | | Perinatal Outreach | |
| Arkansas Dept. of Health<br>Section of Maternal and<br>Child Health<br>4815 Markham St.<br>Little Rock, AR<br>Deborah Bryant, M.D. | | Medical Assistance | |
| **CALIFORNIA** | | | |
| The Rectory/<br>San Pablo, CA | $150,000 | Residential Social Model | 10 women<br>5 children |
| Via Avanta/<br>Pacoima, CA | $221,000 | Residential drug-free treatment services | 16 women |
| Kiva House/<br>Lakeside, CA | $235,000 | Residential drug-free treatment services | 34 women<br>6 children |
| **COLORADO** | | | |
| Addiction Research<br>Treatment Services<br>Denver, CO | | Outpatient Methadone<br>Residential, OP | |
| Boulder Mental Health | | Outpatient | |
| Substance Abuse Svc. | | Outpatient Methadone | |
| Drug Abuse and Alcohol | | Outpatient | |
| Pueblo Treatment Services | | Detox, Residential, Outpatient | |
| Region Six Alcohol &<br>Drug Abuse | | Detox, Residential, Outpatient | |
| Darrengo Alcohol Recovery Unit | | Detox, Residential, Outpatient | |
| Island Grove, CO | | Detox, Residential, Outpatient | |

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| **CONNECTICUT** | | | |
| Crossroads<br>New Haven, CT | $ 119,920 | Residential/Women | 10 beds |
| Hartford Dispensary<br>Hartford, CT | $1,330,135 | Methadone/Available for Pregnant women | |
| Liberation Programs<br>Stamford, CT | $ 201,984 | Methadone | 1,786 slots |
| APT Foundation<br>New Haven, CT | $ 770,016 | Methadone | |
| CT Counseling Ctr.<br>South Norwalk, CT | $ 333,355 | Methadone | |
| Regional Network of Programs, Inc.<br>Bridgeport, CT | $ 776,785 | Methadone | |
| **DELAWARE** | | | |
| Brandywine Cnslng. and Diagnostic Center<br>Wilmington, DE | $ 45,000 | Prevention | 1,200 |
| **DISTRICT OF COLUBMIA** | | | |
| Warren Service Clinic | $ 330,300 | Treatment, Intervention<br>Prevention | 511 |
| **FLORIDA** | | | |
| Lakeview Center<br>1221 W. Lakeview Ave<br>Building H<br>Pensacola, FL 32501 | | Full Continuum | |
| Temporary Living Center<br>1677 Piedmont-Wekiva Road<br>Apoka, FL 32703 | | Full Continuum | |
| Southwest Florida Addiction Services, Inc.<br>2562 Dixie Parkway<br>Fort Myers, FL 33901 | | Full Continuum | |
| Gratitude Guild<br>317 North Lakeside Court<br>West Palm Beach, FL 33407 | | Full Continuum | |
| Western Palm Beach County Mental Health<br>10224 Northwest Avenue, D<br>Belle Glades, FL 33430 | | Full Continuum | |
| Broward Addiction Rehabilitation Center<br>1011 Southwest 2nd Court<br>Fort Lauderdale, FL 33312 | | Full Continuum | |

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| **FLORIDA** (cont'd) | | | |
| Family Health Center<br>5361 Northwest Services<br>111 Northwest 1st Street<br>Suite 2110<br>Miami, FL 33128 | | Full Continuum | |
| Avalon Center<br>41-F Hoffman Drive<br>Gulf Breeze, FL 32561 | | Support Service | |
| C.O.P.E. Center<br>112 W. Nelson Avenue<br>Defuniak Springs, FL 33433 | | Support Service | |
| Community Drug & Alcohol Commission<br>803 N. Panafox Street<br>Pensacola, FL 32501 | | Support Service | |
| North Florida Mental Health<br>Michigan Street<br>Route 10, Box 418<br>Lake City, FL 32055 | | Support Service | |
| River Region Human Services<br>421 Church Street, Suite 702<br>Jacksonville, FL 33201 | | Support Service | |
| Okaloosa Guidance Clinic<br>205 Shell Avenue<br>Fort Walton Beach, FL 32548 | | Full Continuum | |
| Apalachee Center for Human Services Center<br>Post Office Box 1782<br>Tallahassee, FL 32304 | | Full Continuum | |
| Chemical Addiction Recovery Effort<br>Post Office Box 1517<br>2250 Jenks Avenue<br>Suite C<br>Panama City, FL 32402 | | Full Continuum | |
| Marion Citrus Mental Health Center<br>717 SW Martin Luther King Jr. Blvd.<br>Ocala, FL 32674 | | Full Continuum | |
| Gateway Community Services<br>555 Stockton Street<br>Jacksonville, FL 32204 | | Full Continuum | |
| Stewart Treatment Center<br>124 Michigan Avenue<br>Daytona Beach, FL 32014 | | Full Continuum | |
| Operation PAR<br>10901-C Roosevelt Blvd., #1000<br>St. Petersburg, FL 33716 | | Full Continuum | |

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| **FLORIDA** (cont'd) | | | |
| DACCO<br>3200 Henderson Blvd.<br>Tampa, FL 33609 | | Full Continuum | |
| ACTS<br>4211 E. Busch Blvd.<br>Suite H<br>Tampa, FL 33617 | | Full Continuum | |
| Tri-County Addictions<br>Rehabilitations Services<br>2725 Hwy, 60 E<br>Bartow, FL 33838 | | Full Continuum | |
| Bradford, Union, Putnam<br>Health Care Services<br>Post Office Box 399<br>Starke, FL 32091 | | Support Service | |
| Human Development Center<br>Post Office Box 428<br>New Port Richey, FL | | Support Service | |
| Manatee Glens Corporation<br>402 43rd Street, West<br>Bradenton, FL 34209 | | Support Service | |
| Center for Women<br>305 S. Hyde Park Avenue<br>Tampa, FL 33606 | | Support Service | |
| Center for Drug-Free Living<br>100 W. Columbia Street<br>Orlando, FL 32806 | | Support Service | |
| Lee Mental Health Center<br>1858 Suncoast Lane<br>Fort Myers, FL 33905 | | Support Service | |
| Coastal Recovery Center<br>1670 Main Street, Suite 201<br>Sarasota, FL 34236 | | Support Service | |
| Indian River Community<br>Mental Health<br>714 Avenue, H<br>Fort Pierce, FL 34950 | | Support Service | |
| Alpha Health Services<br>3530 Okeechobee Road, #13<br>Post Office box 2256<br>Fort Pierce, FL 34954 | | Support Service | |
| Mental Health Center of the<br>Lower Keys<br>Post Office Box 488<br>Key West, FL 33041 | | Support Service | |
| The Village<br>Partners in Recovery<br>3180 Biscayne Blvd.<br>Miami, FL 33137 | | Support Service | |

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| **FLORIDA** (cont'd) | | | |
| Concept House, Inc.<br>162 Northeast 49th Street<br>Miami, FL 33137 | | Support Service | |
| Here's Help<br>12645 South Dixie Highway<br>Miami, FL 33156 | | Support Service | |

- Federal ADAMHA Block Grant dollars (approximately $4.8 million) were made available to provide services for at-risk women. Specific treatment programs for pregnant women offer a "package" of services that includes residential and day treatment with support services of vocation/education counselors and an intervention specialist (case manager).

| | | | |
|---|---|---|---|
| **GEORGIA** | | | |
| Fulton County Women's Program | $ N/A | Residential and Family Treatment | N/A |
| **IDAHO** | | | |
| Jemhaven/Boise | $ 68,883 | Women's partial care | |
| **ILLINOIS** | | | |
| Project Safe (12 locations) | $ 880,000 | Outreach, Intensive Outpatient, Parent Training | 540 |
| Drug Free Families w/a Future (16 locations) | $ 600,000 | Outreach, Case Management | 2,570 |
| Maryville | $ 823,672 | Detox, residential | 225 |
| Haymarket House | $ 659,620 | Detox, residential | |
| Women's Treatment Center | $1,900,000 | Detox, residential<br>Outpatient | 900 |
| Illinois Solicitation for New Women's Service | $1,020,000 | Outpatient<br>Residential | 1,130 |
| Illinois Perinatal Addiction Prevention | $ 71,500 | Primary Prevention Targeting Young Women | |
| **INDIANA** | | | |
| Near East-Side Multi-Service Center Indianapolis | $110,000 | Intervention | 75 |
| **KANSAS** | | | |
| First Step House Lawrence | $ 15,517 | Reintegration | 57 |
| Sedgwick Co. Alcoholism Treatment--Women Wichita | $ 55,800 | Outpatient | 990 |

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| Johnson Co. Substance Abuse Women's Prevention Mission | $ 41,010 | Prevention | 250 |
| Women's Recovery Center of DCCA Topeka | $ 320,000 | Women with Children/ Intermediate | |

**KENTUCKY**

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| JADAC Louisville | $ 5,980 | Training for Medical Students | 140 |

Comments: Kentucky's data system currently does not collect information about pregnancy. All of our treatment programs are available to women (including pregnant women). Many of our prevention programs focus on fetal alcohol syndrome. Our women's Halfway house has had some pregnant clients in the past year (number unknown).

**MAINE**

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| Statewide | $ 48,500 | Intervention, Prevention | |

**MASSACHUSETTS**

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| New Day/Cambridge | $ 324,863 | Residential rehab | 21 |
| Trustees/Boston | $ 212,439 | Residential rehab | N/A |
| Trustees/Boston | $ 40,000 | Methadone Detox and Counseling | N/A |

**MICHIGAN**

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| Hutzel Recovery Center/Detroit | $1,259,755 | O/P, day care, prevention | 651 |

**MINNESOTA**

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| Eden Day Minneapolis | $ 148,000 | Treatment, Child Care | 36 |
| St. Cloud Hospital | $ 100,000 | Halfway House | 25 |
| Turning Point Minneapolis | $ 147,000 | Treatment, Child Care | 36 |
| Ramsey County | $ 150,000 | Intervention, Treatment | 75 |
| Hennepin County | $ 150,000 | Intervention, Treatment | 75 |

**MISSOURI**

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| Hannibal Council on Alcohol & Drug Abuse<br>121 South 10th Street<br>Hannibal, MO 63401 | $ 457,550 | | 9 |
| Task Force for Women Alcoholics<br>P.O. Box 090595<br>Kansas City, MO 64109 | $ 505,125 | Residential | 10 |

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| Family Counseling Center of MO (FCC)<br>1001 East Walnut<br>Suite 102<br>Colombia, MO 65201 | $ 444,749 | Residential | 9 |
| Bridgeway Cnslng. Services, Inc.<br>114 North Main, Suite 4<br>St. Charles, MO 63301 | $ 489,298 | Residential | 9 |
| Family Self-Help Center<br>1809 Connor Street<br>P.O. Box 1765<br>Joplin, MO 64802 | $ 415,512 | Residential | 17 |
| Cape Girardeau Wiser, Inc.<br>1111 Linden Street<br>Cape Girardeau, MO 63701 | $ 468,516 | Residential | 10 |
| Lakes Country Rehabilitation Center<br>2626 W. College Rd.<br>Springfield, MO 65802 | $ 415,512 | Residential | 13 |

## NEBRASKA

| | | | |
|---|---|---|---|
| Fetal Alcohol Syndrome/Lincoln | $ 73,2261 | Information | 450 |
| Fetal Alcohol Syndrome/Lincoln | $ 74,000 | Information | 600 |

## NEVADA

Such services currently limited; however, we are in the process of developing an RFP for such services. The funding source is the increase in our FY 90 ADMS grant.

## NEW HAMPSHIRE

| | | | |
|---|---|---|---|
| Chemical Dependency Family Counseling | $ 45,000 | Education & Support<br>Outpatient Counseling<br>Referral, Intervention | |
| Hospital Detox | $ 100,000 | | |
| Halfway House for Women | $ 154,477 | | |
| Rehab Programs | $ 744,695 | 28 day rehab | |

## NEW JERSEY

| | | | |
|---|---|---|---|
| FAS Project | $ 50,000 | Prevention | 10,000 |
| 28-day Residential Treatment for Pregnant Women | $ 1,000,000 | Residential Treatment | 150 |
| Demonstration Project | 300,000 | OPT service for pregnant women | 5 |

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| **NEW JERSEY** (cont'd) | | | |
| 6 Treatment agencies accept pregnant women though the program is not exclusively for pregnant women | 460,000 | OPT for Women & Children & Pregnant Women | 89 |
| **NEW YORK** | | | |
| Odyssey House/NYC | $ 252,000 | Residential Treatment | 12 |
| PAAM Pregnant Addicts & Addicted Mothers/NYC | $ 1,050,000 | Outpatient/Treatment | 150 |
| **NORTH CAROLINA** | | | |
| Robeson Health Care Pembroke, NC | $ 150,000 | Assessment, treatment referral and aftercare for pregnant, substance abusing women | 35 |
| **PUERTO RICO** | | | |
| CEDE San Juan | N/A | Detoxification | 14 |
| Drug Free Out-Patient | N/A | Psychosocial | 2 |
| Aguadilla, Arecibo Bayamon, Caguas, Carolina, Humacao, Guayana, Mayaguez, Ponce, Metropolitan | N/A | Information and Education: Emphasis on Fetal Alcohol Syndrome | 16 |

**SOUTH CAROLINA**

We have no programs specifically targeting pregnant women, although many of the programs we support work in close collaboration with family planning and pre-natal care programs of county health departments.

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| **TEXAS** | | | |
| Austin Family House | $ 240,482 | Residential for Women & Children | 8 children<br>8 adults |
| Nexus/Dallas | $ 384,360 | Residential for Women | 205 |
| Sabine Valley MHMR/Longview | $ 218,506 | Residential for Women | N A |
| Association for Advancement of Mexican Americans | $ 20,000 | Intervention | 231 |
| Workers Assistance Program/Austin | $ 71,625 | EAP for Women | 5,434 |
| **UTAH** | | | |
| Community Counseling Center, Salt Lake City | $ 200,000 | Counseling, education, Medical support | |

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| Salt Lake City Community Counseling | | In-home nursing Counseling, referral | 10 |
| **VERMONT** | | | |
| Statewide | $ 40,000 | Perinatal Screening Education | 1,350 |
| Statewide | $ 40,000 | Support Groups for Women in Treatment | 1,100 |
| **VIRGINIA** | | | |
| Center for Perinatal Addictions Medical College Richmond, VA | $ 65,000 | Medical, Psychotherapy, Psych-Social Therapy | 86 |
| **VIRGIN ISLANDS** | | | |
| SAS/Knud Hansen Complex | | Information to Physicians | 28 |
| **WISCONSIN** | | | |
| Meta House for Women and Children Milwaukee, GA | $ 50,000 | Residential/IV Drug | 30 |
| ART Women's Treatment Program Dane County | $ 200,000 | Day Services/Outpatient Intervention | 150 |
| Women Reaching Women (Statewide) | $ 62,000 | Prevention/Advocacy | 2, |

## APPENDIX II

### EXAMPLES OF SPECIAL TREATMENT, INTERVENTION OR PREVENTION PROGRAMS FOR AIDS/HIV INFECTED OR AT-RISK PERSONS ON A STATE-BY-STATE BASIS

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| **ALASKA** | | | |
| CDP/STOP AIDS/Anchorage | $44,000 | Education - Outreach | 2,500 |
| | | Risk Reduction Counseling | 300 |
| | | Blood Draws - HIV Testing | 65 |
| | | Pre/Post HIV Testing and Counseling | 100 |
| | | Education - Outreach | 1,000 |
| SADATP/AIDS/Fairbanks | $38,200 | Risk Reduction Counseling | 100 |
| | | Blood Draws - HIV Testing | 60 |
| | | Pre/Post HIV Testing and Counseling | 60 |
| **ARKANSAS** | | | |
| AIDS/STD Unit of the Arkansas Department of Health, Little Rock, AR | Federally funded through CDC | HIV Testing with Pre-test and Post-test Counseling | 1,350/mo. |
| Comments: For more information about the testing and counseling services contact Robin Bailey, AIDS/STD Unite at (501) 661-2315. | | | |
| **CALIFORNIA** | | | |
| Coupon program/ Monterey Co. | $29,000 | Outpatient Detox | 377 |
| Prostitutes/ San Bernadino | $97,000 | Residential Methadone maintenance | 32 |
| Bay View/ Hunter's Point | $114,000 | Outpatient drug-free outreach | 1,200 |
| Siskiyou Co. Alcohol & Drug Svcs. | $21,000 | IVDU evaluation counseling & referral | 75 |
| **COLORADO** | | | |
| CO Dept. of Health | $1,339,000 | Education, HIV testing, counseling | |
| El Paso County Project 90 | $120,000 | Research & Treatment | |
| Project Safe | $250,000 | Street Outreach Effectiveness | |
| Boulder Needle Exchange Project | $ 20,000 from county funds | | |
| Colorado State Hospital Psychiatric Residential Treatment Program | $363,440 | Treatment | 150 |

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| CONNECTICUT | | | |
| | (State money) | | |
| Human Resources<br>of New Britain<br>180 Clinton Street<br>New Britain, CT 06053 | $ 50,000 | Prevention | |
| L & M Health Care,<br>5356 Montauk Avenue<br>New London, CT 06320 | $ 50,000 | Prevention | |
| Regional Network of<br>Programs, Inc.<br>171 Golden Hill St.<br>Bridgeport, CT 06604 | $ 124,895 | Prevention | |
| Perception Programs<br>214 Valley Street<br>P.O. Box 407<br>Willimantic, CT 06540 | $ 38,630 | Prevention | |
| | (Federal money) | | |
| Apt Foundation<br>904 Howard Avenue<br>Suite 2A<br>New Haven, CT 06519 | $ 54,901 | HIV Counseling/Testing | |
| Regional Network<br>of Programs, Inc.<br>171 Golden Hill Street<br>Stamford, CT 06901 | $ 43,120 | HIV Counseling/Testing | |
| Hartford Dispensary<br>345 Main Street<br>Hartford, CT 06106 | $ 85,291 | HIV Counseling/Testing | |
| Liberation Programs<br>119 Main Street<br>Stamford, CT 06901 | $ 36,058 | HIV Counseling/Testing | |
| CT Counseling Ctr<br>951 Chase Pkwy.<br>Waterbury, CT 06708 | $ 23,104 | HIV Counseling/Testing | |
| CT Counseling<br>Ctrs., Inc. | $ 25,130 | HIV Counseling/Testing | |
| Central Naugatuck<br>Valley Consortium for<br>Alcoholism Services<br>1875 Thomaston Avenue<br>Waterbury, CT 06704 | $ 62,425 | AIDS Risk Reduction<br>Outreach Workers | |
| Hill Health Center<br>400 Columbus Avenue<br>New Haven, CT 06519 | $ 47,569 | AIDS Risk Reduction<br>Outreach Workers | |
| Middlesex Mem. Hosp<br>Outpatient Alcohol Service<br>28 Crescent Street<br>Middletown, CT 06457 | $ 31,713 | AIDS Risk Reduction<br>Outreach Workers | |
| Danbury Health Dept.<br>20 West Street<br>Danbury, CT 06810 | $ 31,713 | AIDS Risk Reduction<br>Outreach Workers | |

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| **CONNECTICUT** (cont'd) | | | |
| Stamford Health Dept.<br>888 Washington Blvd.<br>P.O. Box 10152<br>Stamford, CT 06904-2152 | $ 62,425 | AIDS Risk Reduction<br>Outreach Workers | |
| Hartford Dispensary<br>345 Main Street<br>Hartford, CT 06106 | $ 62,425 | AIDS Risk Reduction<br>Outreach Workers | |
| Regional Network of Programs, Inc.<br>171 Golden Hill Street<br>Bridgeport, CT 06604 | $ 19,425 | AIDS Risk Reduction<br>Outreach Workers | |
| **DELAWARE** | | | |
| Brandywine Cnslng. and Diagnostic Center<br>Wilmington, DE | $ 45,000 | Prevention and Outreach | 2,500 |
| Kent Counseling Center<br>Dover, DE | $ 23,000 | Prevention and Outreach | 850 |
| **DISTRICT OF COLUMBIA** | | | |
| ADASA AIDS Demonstration Project | $ 1,560,000 | HIV Testing, AIDS Education, Intervention | 1,758 |
| **GEORGIA** | | | |
| AIDS Outreach Counselors | $ 196,191 | Outreach/Educators | 10,000 |
| **ILLINOIS** | | | |
| Chicago Integrate Care Project | $ 1,300,000 | Comprehensive Primary Care<br>HIV Services | 3,250 |
| Project Stable | $ 169,798 | Minimalist Treatment Prototype | 135 |
| Health Education Risk Reduction | $ 106,500 | Health Education<br>HIV, risk reduction<br>IDU's & Families | 1,000 |
| Counseling & Testing | $ 106,500 | HIV Testing & Counseling | 2,000 |
| Treatment Vans | $ 180,000 | Outreach, minimalist counseling, medication<br>HIV counseling & testing<br>Health screening | 225 |

**INDIANA**

There are no programs that provide a special focus on AIDS. Rather, a number of treatment services address the AIDS issue in service delivery.

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| **KENTUCKY** | | | |
| Louisville-Jefferson County Board of Health | $ 150,000 | Methadone Maint. | 46 |
| Bluegrass Regional MH-MR Board Lexington | | Methadone, Outpatient Residential | 266 |
| Seven Counties Services Louisville | | Outpatient, Detox Residential | 123 |
| (State total [including other providers] | | | 807 |

**LOUISIANA**

Comments: Treatment, intervention, and prevention programs for AIDS/HIV clients is being provided to our clinics by the Louisiana AIDS Prevention Surveillance Program.

**MAINE**

| | | | |
|---|---|---|---|
| Portland, Lewistown Auburn | $ 41,300 | Street Education | n/a |

(Note: FY 1989 I.V. set aside funds have been distributed to those programs with high percentage of I.V. users.

Comments: Based on data from our newly implemented automated management information system, nearly 18% of the clients admitted during the first quarter of FY 90 reported a history of I.V. use.

| | | | |
|---|---|---|---|
| **MASSACHUSETTS** | | | |
| Trustees/Boston | $ 60,000 | Drop-in counseling and testing | |
| Victory/Boston | $ 200,000 | Client education, advocacy & support | |
| Social Justice/ Framingham | $ 93,110 | Services for incarcerated women | |
| NUVA/Gloucester | $ 30,000 | Community Outreach/ advocacy | |
| **MARYLAND** | | | |
| Street Outreach AIDS Project (SOAP) | $ 370,000 | Education & Referral | 25,000 |
| **MICHIGAN** | | | |
| Detroit Dept. Health | $ 144,258 | Education, Outreach Counseling, Testing | N/A |
| **MINNESOTA** | | | |
| Counselor Training | $ 36,000 | Technical Assist. | 500 |
| MN. Consolidates Treatment Fund | $ 560,000 | IV Treatment | 200 |
| Special Tx Projects | $ 130,000 | IV Treatment | 50 |

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| **MISSOURI** | | | |
| Rogers Center<br>Kansas City | $ 400,000 | Methadone,OPT | 100 |
| Swope Parkway<br>Kansas City | $ 700,000 | Residential, OPT | 300 |
| Ad Hoc Group<br>Kansas City | $ 100,000 | Outreach | N/A |
| **NEBRASKA** | | | |
| Equilibria<br>Omaha | $ 101,954 | Counseling, Information | 150 |
| Health Dept.<br>Statewide | | Information | 750 |

Comments: Nebraska Teratogen Project serves physicians, nurses, pharmacists and other health professionals caring for pregnant women. Hattie B. Munroe Center for Human Genetics, Meyers Children's Rehabilitation Inst. University of Nebraska Medical Center, 4420 Dewey Ave., Omaha, NE 68105-1018.

| | | | |
|---|---|---|---|
| **NEVADA** | | | |
| NV Treatment Ctr.<br>Las Vegas, NV | $ 75,000 | Outreach and Methadone Maintenance | 500 |
| Bridge Counseling<br>Las Vegas, NV | $ 64,818 | Outreach, Education Outpatient Counseling | 800 |
| NASAC<br>Las Vegas, NV | $ 15,000 | Outreach | 100 |
| NV AIDS Foundation<br>Reno, NV | $ 8,000 | Education | 200 |
| **NEW HAMPSHIRE** | | | |
| ARROW | $ 60,000 | Outreach to IV drug users Training & Ed. to Providers Detox | |

Comments: Because New Hampshire is geographically small and not particularly population dense, we have a number of services that are statewide in catchment area. They may be placed in a rural setting, but serve all folks eligible state-wide. Example: Odyssey House Therapeutic Community for adolescents and Marathon House of adults.

| | | | |
|---|---|---|---|
| **NEW JERSEY** | | | |
| TAP Liaison<br>(5 programs) | $ 180,000 | Linkage with HIV--early intervention | just starting |
| Newark Community Health Center | $ 55,000/<br>6 months | Substance abuse counseling in a Family Health Ctr | just starting |

About 3 million dollars in funding for various HIV projects is allocated to drug treatment centers by the Division of AIDS. Includes AIDS Coordinator, street workers, residential beds, mobile vans, medical day care.

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| **NEW YORK** | | | |
| AIDS Outreach | $ 1,500,000 | Street Outreach | 27,000 |
| Holistic Outreach & Mobile Education | $ 1,600,000 | Mobile Outreach | 7,000 |
| HIV Coordinators NYC | $ 4,500,000 | Prev./Int. | 36,000 |
| Counseling, Testing & Partner Notification NYC/Buffalo | $ 4,000,000 | Prev./Int. | 16,000 |
| T.B. Prevention | $ 950,000 | Prev./Int. | 10,750 |
| **NORTH CAROLINA** | | | |
| Drug Action of Wake Co./Raleigh | $ 37,208 | Outreach | 78 |
| Step One Winston-Salem | $ 36,286 | Outreach | 50<br>(500 referrals) |

Comments: Drug Action of Wake (Raleigh), Sycamore Center (Greensboro), High Point Drug Action Council, Alcohol and Drug Abuse Treatment Center/Butner, Alcohol and Drug Abuse Treatment Center/Black Mountain, Step One (Winston-Salem), Pitt Co. MCH (Greenville) , Durham Co. MCH, and Cape Fear Substance Abuse Center are all HIV testing sites and are funded through the AIDS Control Branch of the Dept. of Environment, Health and Natural Resources.

**OHIO**

Total Number of Cases (IVDU) in Ohio
113 (7 percent)     60 are dead (53 percent)

Total Number of Cases (Gay and Drugs) in Ohio
120 (7 percent)     71 are dead (59 percent)

Total Number of Cases (Hetersexual Contact from IVDU) in Ohio
31
Total Number of Cases (Babies) IVDU or through sexual contact with IVDU in Ohio
9

**PUERTO RICO**

| | | | |
|---|---|---|---|
| Drug Free Out-Patient | N/A | Psychosocial | 16,977 |
| Residential | N/A | Long-Term-psycho-Social | 466 |
| Methadone | N/A | Maintenance | 1,589 |
| Acupuncture | N/A | Detoxification | 205 |
| Sexual Partners of IV Drug Users (Tu Mujer)/Public Housings of Metropolitan area | $ 356,000 | Pre- & Post Counseling Individual and group Counseling, HIV Blood Test | 344 |

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| P.R. AIDS Community Outreach and Counseling Demonstration Project (Rio Piedras, Bayamon, Puerta de Tierra) | $ 939,405 | Pre- & Post Counseling | 611 |
| All Prevention Centers | N/A | Information About AIDS in relation to Drug Abuse targeted to High & Low Risk Population | N/A |

**SOUTH CAROLINA**

No specifically targeted programs, although AIDS/HIV education has been incorporated as a component of most treatment programs with whom this agency contracts.

**TENNESSEE**

| | | | |
|---|---|---|---|
| MeHarry CMHC Nashville, TN | $ 150,000 | AIDS Walk-In | 3,000 |
| Sickle Cell Council Memphis, TN | $ 150,000 | AIDS Walk-in | 3,000 |
| Associated Rural Development, Memphis | $ 75,000 | AIDS Walk-In | 1,500 |

**TEXAS**

| | | | |
|---|---|---|---|
| Care Unit | $ 195,000 | HIV Counseling, Testing, Risk Assessment | 888 |
| Austin Travis County MHMR | $ 105,000 | Outreach to IV Community | 635 |
| Lubbock Regional MHMR | $ 85,000 | Information | 75 |
| | $ 100,000 | Information | 29 |
| Pirate Project | $ 59,000 | Information | 761 |
| Corpus Christi | $ 85,000 | Information | 264 |

Comments: Special HIV projects in treatment programs have been dually funded and coordinated by TCADA and the Texas Dept. of Health.

**VERMONT**

| | | | |
|---|---|---|---|
| Statewide | $ 40,000 | AIDS Education for all new TX Admissions | 4,000 |
| Champlain Drug Burlington | $ 10,000 | Outreach to Needle Users | 250 |
| Vermont Cares Burlington | $ 15,700 | AIDS Training/Education | 250 |

**VIRGINIA**

| | | | |
|---|---|---|---|
| Virginia Beach Street Outreach and Treatment Services | $ 63,300 | Drug Ed/Prevention | 500 |

| Name/Location | Funding Level | Types of Services | # Served |
|---|---|---|---|
| **VIRGIN ISLANDS** | | | |
| SAS/Knud Hansen Complex | | Pre/Post testing Counseling HIV Testing | |
| **WEST VIRGINIA** | | | |
| No programs specifically for AIDS/HIV infected or at-risk persons. An AIDS unit provides training to treatment program staff, and prevention for the general public. | | | |
| **WISCONSIN** | | | |
| Statewide | $ 1,354,000 | Street Outreach and outpatient treatment | |

# STATEMENT OF THE FEDERATION OF BEHAVIORAL, PSYCHOLOGICAL AND COGNITIVE SCIENCES

On behalf of the fifteen scientific societies and more than 130 university departments and research centers that make up the Federation of Behavioral, Psychological and Cognitive Sciences, I thank the Subcommittee for affording us the opportunity to offer our views on the fiscal year 1991 appropriation requests for the Department of Education, the National Institutes of Health, and the Alcohol, Drug Abuse and Mental Health Administration. This statement is also being put forth on behalf of the American Educational Research Association (AERA) which represents more than 15,000 educators and educational researchers.

## DEPARTMENT OF EDUCATION

Of particular interest to members of the Federation and the AERA is the Department of Education request for the office of Educational Research and Improvement (OERI). We find in the President's request a good deal that is encouraging. We also find reason for caution. Fiscal year 1991 is a critical year for educational research because decisions will be made on between 12 and 18 educational research centers. If Congress endorses the President's request for an additional $4 million for research center funding, then it will be possible to fund the ten centers that would be up for recompetition in any case owing to completion of their previous funding cycle during the current fiscal year. In addition, two centers to address new educational challenges identified by the Department of Education as priorities would be funded. And six centers to address needs identified by the President and the Governors would also be funded. Without full funding for the centers, no more than twelve would be supported. Elected representatives from the state houses to the White House and from the state assemblies to the Congress have decried the condition of American education and have called for measures to be taken to correct the problems. The educational research centers are a crucial part of the effort to correct the problems. Research on learning, teaching, and administration provide the wherewithal to make sound and effective changes. Without these centers to produce scientifically verified methods of improving education, the educational system is prey to whatever idea might be in vogue at the moment. Lasting positive change requires a good deal of painstaking scientific preparation as well as ongoing evaluation. The centers provide the scientific base for educational improvement. We strongly urge the Subcommittee to recommend full funding of all 18 educational research centers.

Of much more modest proportions is the request for non-center educational research funding at OERI. For years non-center research in education has languished for want of a healthy budget. The half million dollars that supported this effort for several years funded only six to eight research projects per year. This fiscal year the Congress approved a budget of $750,000. For FY91, the President requests $1 million. The centers focus effort on specific subject areas. The function of investigator initiated research is to explore areas that are not covered by the center missions. Both kinds of research are absolutely essential for the advancement of education. We are pleased that the President has asked for an increase in this item. While $1 million is far short of what is needed, we applaud the trend toward increased funding and urge this Subcommittee to recommend a supplement to the President's request for investigator initiated research. It is our belief that education will best be served by a combination of targeted research represented by the centers, and innovative research represented by individual investigator initiated research. We also believe that there is a need for demonstration research. That is, research that takes the results of more basic research and demonstrates its effective application in the classroom. We understand that a small program of this type may be possible in FY 1991. If that is the case, it will mark the first time in many years that the Office of Educational Research and Improvement has been able to fund an at least nominally balanced portfolio of educational research.

Educational research is underfunded. We, therefore, must be encouraged by every effort to improve research funding. It is in this vein that we are heartened by the healthy increase in funding requested for OERI. At the same time, we know that research is strongest when it receives steady, consistent support. The areas for which major new funding is sought for OERI are new areas related to priorities identified by the President and the Governors. This new funding will not be contributing to the ongoing effort in research, and in some cases the new funding will not go toward actual research. For example, $25 million is requested to recruit school administrators, and $20 million is requested for whatever followup activities are to come out of the education summit. Our concern is that the emphasis on these new programs will mask the basic reality, which is that this nation has not paid enough attention to building a strong program of educational research and application. We hope these new endeavors will prove fruitful, but we cannot emphasize enough that they are not a substitute for a well sustained and ongoing program of strong educational research.

## NATIONAL INSTITUTES OF HEALTH

Our general observation regarding both the NIH and the ADAMHA budgets is that while both request increases, there are two major problems with these budgets that cry out each year ever more loudly for solutions. The first is that they are doing an increasingly poor job of bringing new people into science. The second is that they are very discouraging budgets for those who, perhaps despite their better judgment, have chosen in recent years to become scientists.

To put the matters simply, support for the training of new scientists is becoming more and more inadequate, and the chances for new scientists to find Federal support for their research are rapidly dwindling. The combination of these two problems is like a time bomb. We know from the demographics of the scientific labor force that large numbers of scientists will be retiring over the next decade. If research in the behavioral and biological sciences is to do no more than hold its place, these retiring scientists must be replaced. If the enterprise is to be strengthened, then scientists must be trained at a rate beyond that needed for mere replacement. It seems more and more likely that we will not replace the scientists we will be losing. It takes a very long time to make a scientist. If the problem we see developing is not dealt with soon, it can be guaranteed that health related research in the United States will be in dire straits by the turn of the century.

In part, the problem at NIH and ADAMHA is structural. A decision was made some years back that supporting seasoned investigators over longer time periods would produce a more consistently excellent body of research than would forcing these top investigators to consume vast amounts of time trying to find adequate funding for their research every year or two. The movement toward non-competing grant renewals for top researchers is not unwise as far as it goes. The problem is that, as the budget makes clear, a kind of Faustian trade has been made: The training of new scientists and opportunities for new researchers have been postponed or eliminated to make it possible to fund the longer term support of seasoned researchers. Our organizations represent both newer and more seasoned investigators, so we are keenly attuned to the dilemma. But all of us have to understand that the research budget serves many purposes. It funds the production of knowledge, but just as importantly, it funds the production of those who make the knowledge. If the latter is neglected, the former will eventually suffer.

In FY 1987, NIH was able to fund 6,400 new grants. In FY 1991, NIH expects to be able to fund only 4,600 new grants, and this number will be possible only by downwardly negotiating the funding levels for grants already awarded. Particularly hard hit will be the areas that were underfunded even before the era of downward negotiation. The behavioral and social sciences make up less than four percent of the NIH research budget. Moreover, two of the major areas where these sciences have special contributions to make--child development and aging--have long been underfunded. At the National Institute on Aging, for example, it is expected that only seventeen percent of research proposals *judged by peer review to be worthy of support* will actually be funded. While the funding rate for NIH overall is expected to dip to between twenty and twenty-five percent in FY91, NIA will be among the hardest hit. Discouraged scientists have to wonder how their work can continue when the best researchers have less than one chance in five of receiving support for their work. What scientist in good conscience can enthusiastically lead graduate students into careers of such frustration?

The Congress's own Pepper Commission has recommended in its final report that funding for aging research increase to $1 billion. Considering the aging of the American population, this amount is a prudent goal, and both the Federation and AERA endorse the finding and recommendation of the Commission. In particular, we urge that the following amounts be added to these research categories: $20 million for health and behavior research, $28 million for research on long-term care of older people and their families, $6 million for research on work, retirement and health, and an additional $4.4 million for research on age-related changes in cognitive and behavioral functioning. We join the Consortium of Social Science Associations in making these recommendations.

The National Institute of Child Health and Human Development is also of special interest to our researchers. We wish to emphasize that the President's requested budget for that Institute will require a 12% downward negotiation of competing grants, a 15.5% downward negotiation for noncompeting grants and a $21.6% reduction for ongoing centers. We join many other groups concerned with health research that benefits children in calling on this Subcommittee to recommend an NICHD FY91 funding level of $635,306,000. That is the amount that will be necessary to fund 40% of research proposals judged through peer review to be worthy of funding without requiring downward negotiations of existing grants to make such funding possible. Under the President's request, and with the aforementioned downward negotiations, no more than 22.5% of qualified grants could be funded.

## ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION

As I have outlined, the problems that NIH is experiencing with grant availability, downward negotiations and lack of support for the training of new scientists also are to be found at ADAMHA. If ADAMHA were to only hold its ground, that is, fund FY90 services in FY91, it is estimated that a budget of $994 million would be needed. The President has requested $932 million. In unadjusted terms, this represents a considerable rise in funding over the FY90 level of $851 million. But consider the implications: It will fund 604 competing research grants, 268 fewer than in FY90. That will drop the grant rate from the 33% rate of FY90 to just 20%. And those grants will be funded at amounts that will average at least 8% below the levels recommended by study-section reviewers. We join with some 140 other organizations in recommending that the Congress appropriate $1.197 billion for research and research training at ADAMHA. This figure would allow funding of 40% of proposals judged scientifically worthy of support by peer reviewers without downward negotiation of existing grants.

Many exciting things are going on within ADAMHA that have important implications for the health and well-being of the country's citizens. Thanks to the Congress's passage of legislation making the 1990's the Decade of the Brain, intense efforts at ADAMHA are being focused on finding cures for a number of mental disorders including schizophrenia and manic depression. Breakthroughs in the past decade that have linked behavioral research to neurological substrates for the first time put solutions to these problems--that now consume millions of hospital bed days in this country--within grasp. Related research again linking the brain with observed behaviors offer promise for finding effective ways of blocking the effects of cocaine and heroin on the brain. In effect, the research is pointing the way toward cures for some addictions. Drug abuse, alcoholism, mental disorders, AIDS--these are perhaps the most challenging human problems of our time. Finding solutions to these problems would add significantly to the productivity of the U.S. work force, would vastly improve the health of our citizens, and would free billions of dollars of resources that must now be devoted to chronic care to other purposes. It is hard in a prolonged period of fiscal constraint to make decisions about how to divide resources. One reasonable principle on which to base such decisions is that resources should be devoted to work that has the greatest potential to recover even greater resources from current uses so that they may be used for other purposes. Funding of ADAMHA at the level we and others recommend is just such a sound investment.

# STATEMENT OF THE AMERICAN COLLEGE OF NEUROPSYCHOPHARMACOLOGY

## A. Background of ACNP

The American College of Neuropsychopharmacology ("ACNP") is an interdisciplinary association composed of psychiatrists, neuroscientists, psychologists, pharmacologists, pharmacists, other physicians and key related health care professionals. Its approximately 450 members are elected from across the United States. Members include scientists studying the biological function of the central nervous system and its relationship to the causes and treatment of mental and addictive disorders. The ACNP membership constitutes the most respected scientists in the United States who participate actively in research conducted through grants provided by the three component institutes of the Alcohol, Drug Abuse and Mental Health Administration ("ADAMHA"). We are pleased to have the opportunity to present our views to you, especially because this Congress sits as we begin the "Decade of the Brain."

## B. Comments Concerning Administration Budget Proposal

### 1. Expenditures for Research Remain Insufficient

ACNP is grateful for the increased recognition of the importance of research in combating epidemic drug and alcohol abuse. Within the tight budgetary limitations with which the Administration and the Congress must dwell, an overall increase in research funding of approximately seven percent is significant. The history of lack of funding in this area, however, has caused many of our best investigative scientists to shift from the study of mental and addictive disorders. Substantial and sustained funding opportunities over a period of years is essential to reattract experienced scientists and cultivate the new cadre of bright young minds required to tackle the challenges posed by these disorders.

As has been frequently stated, the Federal Government funds the bulk of basic pharmocologic research. ADAMHA is the major player in terms of funding research on mental and addictive disorders. Of those other diseases for which NIH is responsible, 45 percent of total research funding comes from non-federal sources. For diseases under ADAMHA's purview, less than 15 percent of research support is provided by State and private sources. We believe that a greater portion of drug interdiction resources should be directed to research, and that these resources must continue for a sustained period of time. More resources should be directed toward the development of antagonistic and/or "blocking agents" and to basic research into how brain cells metabolize. New medications resulting from this research could ultimately curtail demand. ADAMHA research initiatives should not be short-changed in the face of huge increases in law enforcement expenditures.

### 2. Significant Progress from Psycopharmacologic Research

ADAMHA funded research has produced dramatic results in a relatively short period of time. A significant portion of the intramural and extramural research funded through ADAMHA is reviewing medications to control or reduce cravings for alcohol and addictive drugs. These researchers are currently pursuing promising leads from animal studies and clinical research with alcoholics, focusing on serotonin antagonists, anti-convulsants, calcium channel blockers, and related agents.

Drugs for the treatment of cocaine addiction now exist in several stages of development. Drugs such as buprenophine and carbamazepine, as reported by Drs. Mendelson and Mello, and Dr. Halikas and others respectively, have provided promising results in human cocaine addicts and primate models. In addition, several drugs have been shown to reduce cocaine self-administration in animal models by antagonizing the neurotransmitter (dopamine) (bromocryptine and new experimental drugs). Unfortunately, these drugs could have side effects which are now being examined that might be of serious concern especially if they were used on a long-term basis. Thus, the search for related and safer drugs must continue.

Grants are also being used to conduct important basic research, treatment demonstration projects, research on financing of care, rigorously designed and evaluated prevention studies and other relevant inquiries. Block-grant set-asides were used in 1989-90 to expand joint data collection efforts of NIDA and NIAAA. Greater efforts have been placed on collaborative efforts to collect information on the prevalence and incidence of alcohol and other drug abuse, characteristics of patients beginning treatment, the number of treatment service providers, and the range of treatments. Funds are also being used to conduct a large prospective study of general hospital admissions to develop reliable estimates of the contribution of alcohol and drug-related morbidity to hospital utilization and costs.

Exciting research is occurring to identify genetic markers for a propensity toward certain conduct. Linked genes can be used as markers for early detection, counseling and preventive intervention. Genes offer short-cuts to understand and treat underlying disease which may involve defective enzymes, transmitters, receptors or other neuronal components.

Clinically valuable research is being conducted on comorbidity, or the significant relationship between alcoholism, drug abuse and mental illness. Successful treatment of addictive disorders in mentally ill persons reduces treatment resistance for the mental disorder and required hospitalizations.

Finally, computer imaging technology is being used to characterize actual physical damage that occurs in the brains of alcoholics and drug addicts, and to identify alterations in various forms of mental illness. This information provides useful early diagnosis techniques and will lead to the development of new treatment approaches.

### 3. The Number of Research Grants Should Be Expanded

It is counterproductive to increase research expenditures by approximately seven percent, but reduce the number of extramural project grants by 12 percent. It has been suggested, for instance, that NIH curtail the increase of new grant applications so that funding for existing grants is stabilized. Such an argument, if applied to ADAMHA, would undermine two important goals of increased research expenditures; (i) to attract bright young minds to pharmocologic research; and (ii) to develop newer and better addictive substance treatments and treatments for disabling mental illnesses. By curtailing grant applications, we turn our back on new and better, and perhaps even novel, ideas that emerge properly from the flow of new information and the development of new methodology. We should seek to stabilize funding for current ideas to extract all that we can from them, but these dollars should not have to compete with dollars for new ideas. Stabilization also should not be used as a justification to accept stagnation. Neither should Congress place limits on what the best and brightest group of scientists can propose through new ideas in order to achieve the missions of the health sciences research agencies. Finally, prospective young researchers need to be encouraged to commit their knowledge, energy and enthusiasm to the field through new funding opportunities to support their research.

4. Rebuild Researcher Pool

The Subcommittee should remember how reductions of research expenditures of 35 percent in the 1970s, and a 35 percent increase to NIH, led unintentionally to a significant reduction of investigators in the neurosciences and psychopharmocology. Attracted by the availability of research grants from NIH, a generation of talented investigators drifted into the behavioral sciences to turn their attentions to cardiac disease, cancer, childhood disorders, and aging. In recent years, ADAMHA research funding has been held at stable dollar amounts despite modest rises in stipends. The number of trainees supported in research has fallen from more than 1,600 annually to less than 1,200 annually. If the 1990s are to succeed as the "Decade of the Brain" in which we achieve dramatic reductions in the incidence of mental illness, alcoholism and drug abuse, additional grants and other resources will be required to cultivate a new generation to tackle the continuing challenges posed by these disorders.

The Nation spends less that one percent of the cost of treating these disorders on research into those conditions according to ADAMHA Administrator Dr. Frederick Goodwin; roughly one-half of the proportion of general medical care costs devoted to NIH research. As virtually the lone provider of research grants in these areas, ADAMHA must have sufficient resources to fund the research of young undergraduate and graduate students. It requires from six to ten years of education, post graduate training and experience to begin to become a contributing scientist. The Congress must improve funding predictability and increase the duration of grants to tailor them to the needs of young researchers in the field. Additionally, funds for training, which currently total less than five percent of the total research budget, must be expanded. Our young need to sustain themselves for the periods necessary to chip away at these monstrously complex medical problems.

5. Support Adoption of Alternative National Drug Control Strategy

In its Alternative National Drug Control Strategy Report, the Senate Judiciary Committee and the International Narcotics Control Caucus enumerated a specific set of proposals directed at attacking this Nation's drug problem. We urge this Subcommittee to work with other Congressional committees to study and implement the Report's recommendations which we enthusiastically support. Those recommendations include:

1. Renew and expand the Medications Development Program to coordinate pharmacotherapeutic research and testing efforts with private industry and the academic community;

2. Modify the Orphan Drug Act to include cocaine treatment medications to create economic incentives for pharmaceutical companies to develop medications for the relatively small addict population;

3. Develop innovative procedures similar to those developed to respond to AIDS to expedite pharmacotherapeutics through the FDA approval process;

4. Prioritize federal spending to ensure that the most urgent and generous attention is given to these designated areas of research; and

5. Require the issuance of an annual Surgeon General's Report on Pharmacotherapy beginning on March 1, 1991.

6. The Politics of Animal Rights

In the pursuit of scientific knowledge, the responsible use of laboratory animals remains essential. A large number of people have confused animal welfare, to which the scientific community is seriously committed, with animal rights. The latter embodies the philosophy that holds that animals and humans are morally equivalent. We support the efforts of Dr. Goodwin and other articulate spokespersons of responsible research who argue that it is folly to subscribe to a movement that places the rights of animals above the health of human beings. It is one thing for the Aspen community to debate placing rights of animals above the fashion whims of humans who support the fur industry. It is quite another to place the right of animals above the health and well-being of the human community. Efforts must be made to direct public attention to the interests and benefits all of us share in animal testing and research.

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# NATIONAL INSTITUTES OF HEALTH

## STATEMENT OF THE ASSOCIATION OF AMERICAN VETERINARY MEDICAL COLLEGES

We appreciate the opportunity to present the recommendations of our two associations which represent all of the veterinary medical teaching and research components of the university system and nearly 50,000 veterinarians.

We are especially concerned with three funding areas within the Public Health Service. These are funding for the National Institutes of Health, the animal based programs within the newly reorganized NIH National Center for Research Resources and, support of health professions education through the Health Resources and Services Administration.

### National Institutes of Health

The Administration's FY 1991 request of $7.930 billion for NIH is falls nearly $400 million short of NIH's estimate of current services. The 4.7 percent proposed increase is well below the projected 5.9 percent increase for the Biomedical Research and Development Price Index for FY 1991. The Administration would continue reducing the size of research project grant awards by significant amounts below study section recommended levels in order to increase the number of competing research projects to 5,095 awards. These cuts result in less research and impede sound financial planning. Reductions in Biomedical Research Support Grants also erode the basic capability of researchers and research institutions to develop responsive and dynamic research capability. Biomedical research and its contributions to health are so important that these projected reductions should not be tolerated.

We recommend that NIH receive a total of $9.237 billion for FY 1991. This will provide critical support in most major areas. Specifically it will restore full funding for research project grants and centers, allow a small amount of growth to provide opportunities for new people and new ideas, and full fund approximately 30 percent of competing research project grant applications. This amount would allow restoration of the Biomedical Research Support Grant program to its FY 1989 level of $56 million and maintain the Administration's proposal for $6 million to support minority institutions. It will also provide support for 12,020 National Research Service Award trainees and support 250 additional research career awards (bringing the total to near 1,800).

## National Center for Research Resources

This unit is a consolidation of the Divisions of Research Services and Research Resources. It provides critical research resources for both human and laboratory animal health research.

**Laboratory Animal Facility Improvement Program.** Since 1985, 135 institutions have received improvement awards under this program. These awards which were matched with institutional funds have been a very positive force in assisting research institutions to improve their animal facilities to meet federal animal welfare regulations and policies. The national need for additional institutional animal facility improvements is estimated to exceed $750 million and approved applications to the Animal Resources Program exceeds the funds available by a 4:1 ratio. We recommend that the FY 1991 budget be increased from the current $10.931 million to no less than $22 million in order to assist institutions to meet the federally mandated standards.

**Core Support for Regional Primate Research Centers.** The seven Regional Primate Centers are essential to the extramural research mission of NIH, ADAMHA and other federal agencies. They provide the research resources for studies of critical importance to understanding many human health problems. In their contributions to human health they provide basic biomedical advancements that are important and immediately applicable to many animal health problems. Rapid advancements in our understanding and potential control of immunodeficiency disease (Human AIDS) is one of the best examples of this critical research. In the thirty years of their operation the facilities have remained virtually unchanged and the core support has steadily eroded over the last 10 years. We recommend that these centers receive construction authority of $32 million extending over a four year period and $7 million annually for the core support of the Centers.

**Biological Models and Materials Resources.** This program was established in the Health Research Extension Act of 1985. It supports the American type culture collection, which distributes over 100,000 cultures to researchers each year and the Yeast Genetic Stock Center which maintains and distributes over 900 strains of yeast used in genome research. In addition it provides some support for the development, validation and use of alternatives to the use of animals in biomedical research. This program was funded at $5.364 million for FY 1990 and the Administration's request for FY 1991 is for $5.356 million. We believe that this program deserves much greater support with special emphasis on the continuation of grants to support research proposals. The Administration's recommendation of $787,000 for research grants would fund only 4 to 6 grants and we believe that this should be increased to a level which would fund at least 30 grants at funding levels up to $250,000 per grant. We recommend that total funding for this program in FY 1991 be raised to $13 million.

## Health Resources and Services Administration

The preparation of highly skilled professionals is the foundation of health care research and health services in our nation. Appropriations for Titles VII and VIII programs support our nations health professions training programs including student loans, scholarships for disadvantaged students, and the recruitment and retention of minorities. They provide critical support to veterinary medical students and to the veterinary medical minority recruitment and retention programs. We support the following:

**Health Education Assistance Loans (HEAL).** Congress should reaffirm its support of the HEAL program and oppose the Administration's proposal to phase out this critically important source of financial assistance. Discontinuation of HEAL would have substantive negative consequences for new students likely to need HEAL loans. Continuation is essential because of limitations placed on the amount students may borrow through the Department of Education.

**HPSL Proposed Transfer of Returned Funds.** Congress should uphold its current position that funds returned from the Health Professions Student Loan (HPSL) program be redistributed to other HPSL revolving funds. The Administration's proposal to transfer to the HEAL insurance fund $15 million from these programs is in opposition to the statutory language. It would siphon resources from a program that helps disadvantaged students who are not able to self-finance their educations and who clearly need this program. The need for transfer is not justified because the Administration projects the Student Loan Insurance Fund to have a positive ending balance of $23.3 million 1991.

**Model Education Special Projects.** Congress should appropriate the full $2.2 million authorization level for these curriculum and faculty development grants. This is a new authority and a relatively small program, but it has the potential of producing excellent results. The Health Resources and Services Administration (HRSA) has identified funding priorities which will help bridge the gaps between current curricular and faculty capabilities and current needs in several critical areas. The major ones are "outcome measurement" relative to faculty effectiveness and instructional methodology, and computer technology and information transfer. Our veterinary medical colleges are committed to the improvement of education and many are competing for the eight grants which will soon be funded for this fiscal year.

We would be pleased to provide additional information supporting these recommendations.

# STATEMENT OF THE NATIONAL ASSOCIATION OF ANOREXIA NERVOSA AND ASSOCIATED DISORDERS

DIETING IS NOT ONLY DANGEROUS - IT CAN BE FATAL. SEVEN MILLION AMERICAN WOMEN AND ONE MILLION MEN FALL VICTIM TO ANOREXIA AND BULIMIA AND ULTIMATELY 10% DIE - A HIGHER MORTALITY THAN ANY OTHER PSYCHIATRIC ILLNESS. OTHERS WILL SUFFER A LIFETIME OF MEDICAL COMPLICATIONS AND PSYCHIATRIC IMPAIRMENT. THESE ILLNESSES STRIKE YOUNG AND OLD, RICH AND POOR, INCLUDING ALL MINORITIES.

OUR NATION'S OBSESSION WITH THINNESS, THE MULTIBILLION DOLLOR DIET INDUSTRY, AND WELL MEANING BUT UNINFORMED PROFESSIONALS DRIVE THIS EPIDEMIC. EVERYONE IS NOW FOCUSING ON THE SCAM OF DIETING, INEFFICIENT, DANGEROUS, AND MULTIBILLION DOLLAR BUSINESS, BUT NO ONE IS FOCUSING ON THE CONSEQUENCES OF DIETING IN CREATING ANOREXIA NERVOSA AND BULIMIA. THE LOSS IS IN LIVES, NOT DOLLARS.

THIS ILLNESS IS TREATABLE IF 1) IDENTIFIED EARLY. 2) TREATED BY TRAINED PROFESSIONALS, AND 3) SUPPLEMENTED BY SUPPORT GROUPS FOR PATIENT AND FAMILY.

TO ACCOMPLISH THIS, WE MUST INCREASE PUBLIC AWARENESS, CREATE PREVENTION PROGRAMS, AND IMPROVE THE ABILITY OF THE PROFESSIONAL COMMUNITY TO PROVIDE EFFECTIVE TREATMENT.

WE FEEL THAT THE HIGHEST PRIORITY SHOULD NOW BE PLACED ON THE 1986 (SO FAR UNIMPLEMENTED) NIMH RECOMMENDATION THAT OUR GOVERNMENT SUPPORT A BROAD PUBLIC EDUCATION PROGRAM - AN AREA IN WHICH ALMOST NOTHING IS BEING UNDERTAKEN THROUGH GOVERNMENT FUNDING.

WE ASK THIS COMMITTEE TO RECOMMEND THAT GRANTS OF $ 5,000,000 BE MADE FOR THE FOLLOWING PURPOSES:

1. SUPPORT OF TRAINING COURSES TO ENABLE HEALTH PROFESSIONALS TO BETTER UNDERSTAND AND TREAT EATING DISORDERS.
2. SUPPORT TO RADICALLY INCREASE PUBLIC AWARENESS THROUGH BROAD PUBLIC EDUCATION/PREVENTION/EARLY DETECTION PROGRAMS.
3. SUPPORT OF LOW COST PROGRAMS TO PROVIDE COMMUNITY SERVICES AND ASSISTANCE FOR THE LARGE NUMBER OF VICTIMS AND FAMILIES.

ANAD HAS BEEN UNDERTAKING SUCH PROGRAMS FOR YEARS, BUT IS VASTLY UNDER-

FUNDED. FINANCIAL ASSISTANCE FOR EDUCATION, PREVENTION AND THE TRAINING OF PROFESSIONALS WOULD RESULT IN MORE APPROPRIATE ATTENTION TO THE ENTIRE SPECTRUM OF PEOPLE WITH EATING DISORDERS.

IN ADDITION, IT IS EXTREMELY IMPORTANT TO MAKE LAXATIVES, EMETICS, DIURETICS AND DIET PILLS AVAILABLE BY PRESCRIPTION OR AT LEAST HAVE THESE PRODUCTS BE PLACED BEHIND THE COUNTERS WHEREVER THEY ARE SOLD. MANUFACTURERS OF THESE PRODUCTS SHOULD BE ENCOURAGED TO ADD WARNINGS OF PRODUCT DANGERS THROUGH MISUSE. IF THEY REFUSE, LEGISLATION SHOULD BE ENACTED TO REQUIRE IT, AS HAS BEEN NECESSARY WITH CIGARETTES AND OTHER PRODUCTS.

STATEMENT OF ANTHONY AND DIANA SMITH:

AT 6 A.M. ON JULY 12, 1989, WE RECEIVED THE MOST TRAGIC TELEPHONE CALL THAT ANY PARENT CAN RECEIVE. AN EMERGENCY ROOM DOCTOR IN PHOENIX, ARIZONA, WAS TELLING US THAT OUR BEAUTIFUL, FUN LOVING, VIVACIOUS DAUGHTER HAD JUST DIED.

NOW THAT SHE IS GONE, IT IS SO MUCH EASIER TO RECALL THE HAPPINESS SHE BROUGHT INTO OUR HOME. IT IS HARD TO TALK ABOUT THE THREE AND A HALF YEARS OF EMOTIONAL AND FINANCIAL HELL THAT WE LIVED THROUGH WITH HER EATING DISORDERS THAT CAUSED HER DEATH. SHE ACTUALLY DIED OF CARDIAC ARREST CAUSED BY AN ELECTROLYTE IMBALANCE DUE TO MALNUTRITION FROM ANOREXIA NERVOSA AND BULIMIA.

NOELLE MOVED WITH US TO A NEW COMMUNITY AFTER HER SOPHOMORE YEAR IN HIGH SCHOOL. IN HER NEW HIGH SCHOOL, THERE WAS A TREMENDOUS PRESSURE TO EXCEL IN THE CLASSROOM. AT THE END OF THE FIRST SEMESTER, HER GRADES WERE NOT AT THE LEVEL OF HER NEW FRIENDS AND SHE FELT SHE WASN'T GOOD ENOUGH EVEN THOUGH SHE HAD MADE THE CHEER LEADING AND SWIMMING SQUADS. THE DAY GRADES CAME OUT, SHE CAME HOME FROM SCHOOL AND DECLARED, " I'M FAT AND I'M GOING TO DO SOMETHING ABOUT IT. " AS WE BEGGED HER TO EAT DAY AFTER DAY, SHE REFUSED TO EAT MORE THAN ONE-HALF SLICE OF DIET TOAST PER DAY. AFTER A WEEK, WE BECAME VERY CONCERNED AND TOOK HER TO THE PHYSICIAN AND TOLD HIM THAT WE FEARED THAT SHE HAD ANOREXIA. HE TOLD US, "NO, THIS IS JUST A PHASE HIGH SCHOOL GIRLS GO THROUGH. HER WEIGHT IS IN THE NORM FOR HER HEIGHT AND AGE." A WEEK LATER WE WERE BACK AGAIN, AND EVEN THOUGH SHE

HAD LOST EIGHT MORE POUNDS , WE WERE TOLD THE SAME THING. TEN DAYS LATER WE PUT HER INTO OUR LOCAL HOSPITAL'S NEW EATING DISORDERS UNIT.

THREE MONTHS AND $ 33,000 LATER, SHE HAD BECOME A SMOKER AND NOW SUFFERED FROM BULIMIA IN ADDITION TO ANOREXIA. SHE HAD ALSO LOST MORE WEIGHT.

WE THEN CHECKED HER INTO A MUCH ADVERTISED EATING DISORDERS UNIT FORTY MILES FROM HOME. THEY ASSURED US THAT THEY WOULD HELP HER GET BETTER. IF THE FIRST PROGRAM WAS BAD, THIS SECOND ONE WAS A TOTAL DISASTER. NOELLE WAS CONSTANTLY BARRAGED WITH QUESTIONS LIKE - WHAT DID YOUR FATHER AND MOTHER DO TO MAKE YOU DO THIS TO YOURSELF? WHAT DID YOUR BROTHERS DO? WHAT DID YOUR OTHER RELATIVES DO? NOELLE TOLD US, " THEY'RE CRAZY. I LOVE YOU GUYS. I WANT TO GO HOME." BUT THIS PROCESS TOOK ITS TOLL. OUR LOVING, TRUSTING DAUGHTER NO LONGER TRUSTED ANY RELATIONSHIP.

AFTER $ 35,000 MORE AND THREE MORE MONTHS, NOELLE HAD GAINED NO MORE WEIGHT AND WAS NOW BITTER TOWARD EVERYONE. AFTER A GREAT DEAL OF CONTROVERSY WITH THIS HOSPITAL'S STAFF AND THEIR INSISTING THAT SHE REMAIN IN THE HOSPITAL, THEY FINALLY CALLED TO SAY THEY COULDN'T HELP HER AND THAT FURTHER HOSPITALIZATION WOULD BE COUNTER PRODUCTIVE.

AT HOME AGAIN, FAMILY RELATIONSHIPS BECAME STRAINED AND CO-EXISTENCE WAS ALMOST IMPOSSIBLE. WE WOULD BUY A WEEK'S GROCERIES AND NOELLE WOULD EAT THEM ALL IN A FRENZIED EATING AND THROWING-UP NITE. WE COULD NO LONGER KEEP GROCERIES IN THE HOUSE AND WERE FORCED TO EAT OUT ALL THE TIME. WE COULDN'T AFFORD TO, AS WE HAD MORTGAGED EVERYTHING TO PAY FOR HER CARE. THE BILLS WERE MOUNTING AND STRAINS OF FINANCES AND EMOTIONS WERE TAKING THEIR TOLL ON OUR FAMILY. IT SEEMED LIKE OUR WORLD WAS COLLAPSING.

NOELLE WAS NOW 18 AND DECIDED TO MOVE OUT. WE WERE TOTALLY EXHAUSTED AND DIDN'T PUT UP MUCH OF AN ARGUMENT WITH HER. HER EATING DISORDER RUINED HER FRIENDSHIPS AND SHE MOVED FROM BAD SITUATIONS TO WORSE.

AFTER SEVERAL MONTHS SHE AGREED TO GO TO THE EATING DISORDERS UNIT AT MENNINGER'S AT TOPEKA, KANSAS. IT WAS A VERY POSITIVE EXPERIENCE FOR EVERYONE OF US AND SHE CAME TO THE REALIZATION THAT SHE HAD HURT HER FAMILY VERY DEEPLY. SHE NEVER AGAIN BEHAVED IRRATIONALLY TOWARD

US. SHE STILL HAD AN EATING DISORDER, BUT SHE MENDED ALL THE WOUNDS WITH HER FAMILY.

AFTER ABOUT SIX MONTHS, SHE STARTED DATING A BEAUTIFUL YOUNG MAN WHO WAS TO BECOME HER FIANCE. SHE WANTED TO SO IMPRESS HIS FAMILY AND FRIENDS AT HIS BROTHER'S WEDDING THAT SHE PROBABLY STARVED HER BODY TO THE POINT THAT SHE COMPLETELY DEPLETED HER BODY OF ELECTROLYTES. SHE FELT THAT THE ONLY WAY SHE COULD BE GOOD ENOUGH WAS TO BE SUPER THIN - NO BODY FAT.

SHE HAD PROMISED TO GO TO THE HOSPITAL AS SOON AS SHE GOT BACK HOME. SHE NEVER MADE IT. SHE CALLED THE NITE BEFORE SHE DIED AND TOLD US THAT SHE LOVED US BOTH AND THAT SHE WOULD BE HOME THREE DAYS LATER. GOD ONLY KNOWS HOW MUCH WE ALL MISS HER.

WE HAVE DEDICATED OUR LIVES TO HELP EATING DISORDERS PATIENTS AND THEIR FAMILIES. WE WANT OTHERS TO BE SPARED FROM THE BAD TREATMENT AND THE RESULTING PAIN AND FINANCIAL BURDEN WE EXPERIENCED. OUR DAUGHTER'S LIFE AND DEATH CANNOT HAVE BEEN IN VAIN. WE WANT UNIFORM CERTIFICATION FOR EATING DISORDERS TREATMENT FACILITIES AND THE THERAPISTS THEY EMPLOY.

PLEASE GRANT SOME FEDERAL MONEY TO TRAIN PEOPLE PROPERLY AND TO FUND RESEARCH INTO THIS AMERICAN TRAGEDY THAT KILLS SO MANY OF ITS VICTIMS.

# STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

Mr. Chairman and Members of the Subcommittee, my name is Gail Cassell and I am Chairman of the Microbiology and Immunology Committee of the Public and Scientific Affairs Board of the American Society for Microbiology (ASM). On behalf of the ASM, I wish to thank the Chairman of the Senate Appropriations Subcommittee on Labor, Health, and Human Services, Education and Related Agencies for the opportunity to express the views of the ASM on the fiscal year (FY) 1991 budget for the National Institutes of Health (NIH).

The American Society for Microbiology is the largest single biological life science society in the world with an active membership of over 36,000. Many of these individuals are engaged in biomedical research and are recipients of awards administered by the NIH.

We are living in an era of unprecedented scientific achievements in biotechnology and molecular biology. Never before have the opportunities been so great to improve the quality of our lives through biomedical research. These advances are largely due to previous support of the NIH. Continued strong support is vital if we are to capitalize on the explosion of scientific opportunity and compete internationally in biotechnology and health. Therefore, the minimal increase of 4.7% proposed in the President's FY 1991 budget for the NIH is of serious concern.

The proposed budget does not even keep pace with the biomedical inflation rate of 5.9%. Under the proposed budgetary constraints, applications ranked even in the 15th percentile will go unfunded by some institutes within the NIH. In addition, the President's budget would continue the harmful policy of cutting grants below study-section recommended levels by 10% for non-competing grants and by 14% for new and competing grants. If funds for AIDS research and the human genome initiative are taken aside, the proposed increase is only 3.7% for the remaining NIH programs, which is significantly below the Administration's 4.2% estimate for overall inflation in 1991.

The proposed NIH budget sends a very discouraging message to highly trained, young scientists who are being squeezed out of the system, as well as to established scientists who face increasing uncertainty about the continuation of their research programs. The proposed low level of increase sends a wrong signal to students whose enrollment in Ph.D. programs in virtually all fields related to biomedical science is declining. The number of bright young people seeking careers in medical research is falling at the very time that we need an influx to exploit an abundance of opportunities to improve treatments and cures for catastrophic diseases such as AIDS, Alzheimer's disease, cancer and other afflictions.

As an alternative to the President's budget, the ASM supports the recommendation of the Ad Hoc Group for Medical Research Funding of $9.2 billion for the NIH in FY 1991. The proposed increase of $1.3 billion over the $7.9 billion requested in the President's budget will help to ensure that NIH maintains its leadership of the nation's biomedical research enterprise in the 1990's.

The Ad Hoc Group's proposal reflects the fact that pressures for continued increases in the NIH budget are greater than ever. This is the case because of rapidly developing scientific advances, the AIDS epidemic, the steeply rising cost of research personnel, supplies and equipment, and the growing recognition that the biomedical research infrastructure needs investment to prevent an erosion of future research productivity. Budgetarily, NIH is now challenged, as never before, to meet the needs of established investigators and at the same time ensure the adequate availability of funds for tomorrow's talented researchers.

The Ad Hoc Group's proposal addresses critical shortfalls in the Administration's request. First, it would restore funding for research project grants at levels recommended by study sections. Funding research project grants at study-section/Council recommended levels is vitally important to ensure the ability of investigators to carry out proposed and approved research. Second, it provides for a measure of growth to take advantage of new opportunities, new people, and new ideas. To achieve these objectives, the Group's proposal would provide money to fund 30% of competing research project grant applications in FY 1991.

The NIH budget requires growth in 1991 and sustained growth in the future. A strong biomedical research program is essential not only to continue the battle against AIDS but to respond to the monumental problems of other infectious diseases. In terms of economic impact, the total cost of caring for various infectious diseases is estimated at over $13 billion for 1990 alone. Influenza and pneumonia remain leading causes of death in the U. S. The rate of syphilis cases has risen 30% in the past two years to the highest level since 1948! In the same two year period, the number of congenital syphilis cases rose by the unbelievable rate of 152%! In the states of Texas and New York there was an all time high in the number of cases of chanchroid, formerly a sexually transmitted disease seen only in developing countries. In my own state of Alabama as well as in others the increase in cases of gonorrhea almost paralleled those of syphilis. The increase in these diseases is greatest among Blacks and Hispanics. Tuberculosis, a re-emerging disease, also disproportionately affects minorities including refugees from third world countries as well as elderly and socioeconomically disadvantaged members of our population. Infant morbidity and mortality associated with infection, particularly those related to sexually transmitted diseases, continue to increase in all groups. We are also challenged by Lyme disease, chronic fatigue syndrome, and human papilloma virus which may be a cause of cervical cancer.

Never before have we had such powerful technology for development of effective diagnostics, antimicrobials, and vaccines for detection and prevention of infectious diseases. However, a great deal of research remains to be done at the basic levels of bacteriology, virology and immunology in order to target specific methods of prevention and cure. The ability of the National Institute of Allergy and Infectious Diseases (NIAID) and the Centers for Disease Control to deal with these critical problems is handicapped because outside the area of AIDS research, budgetary increases have not kept pace with the biomedical inflation rate.

The life-blood of the scientific enterprise is a constant entrance of bright young people into research to replace and add to those leaving. Currently, a crisis exists in the area of training those replacements. The number of new biomedical Ph.D.'s and physician-scientists is unacceptably low. The National Research Council (NRC) has recommended a 41% increase in support for predoctoral students in biomedical sciences to meet the demand expected by the turn of the century. The NRC reports that the demand for biomedical scientists could increase to twice the number of biomedical Ph.D.s produced today. Well-trained scientists are essential for growth of the emerging biotechnology industry in the U. S. but the supply is not meeting the demand. Biotechnology firms are experiencing difficulty in hiring scientists. There is a growing demand for new scientists in academe to replenish openings created by the death and retirement of our aging scientific work force. Competition between academic institutions and the biotechnology industry for scientific personnel is becoming a real problem. Because of these concerns, we support the Ad Hoc Group's proposal to increase funding for research training to $304 million in FY 1991.

The ASM is concerned that minorities remain grossly underrepresented among Ph.D. recipients and overall numerical representation in the biomedical science work force. The Administration's proposed increase to the National Institute for General Medical Sciences (NIGMS)-sponsored Minority Access to Research Careers (MARC), and Minority Biomedical Research Support (MBRS) programs are welcomed, but are deficient in meeting projected national manpower demands. The ASM supports the $16.4 million (professional judgement) level of funding for the MARC program and $35.0 million level for the MBRS (with $10.72 million in additional cofunding from other institutes). The requested increases to the MARC program would approach the National Academy of Sciences-recommended levels and enable the program to extend to include first and second year undergraduates and support competitive fellowships to minority students attending majority institutions. The requested MBRS increases would enable the funding of 7 new institutional awards (totalling 105) for FY 1991 over previous years of no-growth in this important program.

We continue to stress that salaries for NIH senior scientific personnel are not competitive with those in the private sector, and we support legislative and administrative initiatives to begin to address this problem. NIH has lost over 28% of its senior personnel and has not been able to recruit a single senior scientist to its laboratories. Action must be taken to prevent the further loss of top-level scientists from the NIH intramural program.

We support the Ad Hoc Group's recommendation to restore the Biomedical Research Support Grant (BRSG) program to its 1989 level of $56 million. These grants provide medical schools, universities, and colleges with the flexibility to support bright young men and women just starting in a research career, and they play an important role in supporting established researchers who experience delays in funding.

We also support the Ad Hoc Group's request for new funds to improve the intramural research program at the NIH and to renovate the nation's aging scientific physical plant. Improvement of animal facilities constitutes protection against the threat that the progress of research would be severely impeded by the inability to use animals where necessary.

In summary, Mr. Chairman, the American Society for Microbiology believes that adequate funding of the NIH is essential to the health and well being of our nation and we hope that the Congress is able to meet this critical need despite overall budgetary pressures.

Thank you for your consideration, Mr. Chairman.

# STATEMENT OF THE AMERICAN PSYCHOLOGICAL SOCIETY

Mr. Chairman, Members of the Committee:

Thank you for the opportunity to testify concerning Fiscal Year (FY) 1991 appropriations for the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) and the National Institutes of Health (NIH). I am Alan G. Kraut, Executive Director of the American Psychological Society (APS), the national organization devoted to the research base for psychology.

Congress has done much in recent years to support the work of psychological, behavioral, and social scientists. We particularly thank this Committee for its leadership. And we hope that the Committee will continue to insist that ADAMHA and NIH support behavioral and social science research in a way that reflects both the role these sciences play in addressing our nation's health objectives, and the urgency with which those objectives should be pursued.

## Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA)

APS's goal is to ensure that ADAMHA is a broad-based agency that welcomes and encourages different research questions and approaches to substance abuse and mental health. No single research discipline or orientation can provide the answers to the complex questions associated with such diverse issues as prevention, substance abuse treatment, schizophrenia, depression, mental health concerns of minority and other special populations, rural mental health, women's mental health, alcoholism, children's behavioral disorders, AIDS, clinical training, divorce, unemployment, child abuse, crime and delinquency, and the other problems facing us in the 1990's and beyond.

Yet, many ADAMHA research grants programs remain narrowly focused on the biomedical aspects of these issues. For example, in recent years, chronic substance abuse and mental health disorders have commanded increased attention at ADAMHA, but this increased attention has mainly come in the form of biomedical research. We believe this is being done at the expense of behavioral and social science research as well as at the expense of services, training, and demonstration projects. Therefore, we urge that ADAMHA be directed to establish a balanced research agenda that sustains a variety of approaches to the questions of mental health and substance abuse.

### National Institute of Mental Health (NIMH)

We urge the Committee to fund NIMH research at $579.3 million in FY 91. This recommendation represents a significant increase over the President's request of $413.5 million for FY 91, a request which would not even sustain NIMH's current level of research activity. Our recommendation, developed in conjunction with the Mental Health Liaison Group, would provide an increase of $114.1 million over the projected current services level of $465.2 million for FY 91. This would allow NIMH to continue its current level of support for research plus fund additional research activities which have been planned but currently are unfunded or underfunded.

APS is deeply concerned that mental health research is being shortchanged in the proposed budget particularly in comparison to other areas of research. The rate of advancement in our knowledge of depression, schizophrenia, and other major mental health disorders is tied directly to the level of funding received for research in those areas. We believe that the mandate for rapid expansion is clearly expressed in such initiatives as the National Plan for Schizophrenia Research and the National Plan for Research on Child and Adolescent Disorders, which focus on the possible biological and behavioral causes of these conditions, and on ways in which they can be prevented or treated.

National Behavioral Science Research Agenda -- In January, 1990, representatives of over 65 psychological and behavioral science research organizations met in a "Behavioral Science Summit" to begin planning a national research agenda for the behavioral sciences. Their fundamental objective was to develop a comprehensive long-range set of priorities and themes which are consistent with the nation's overall research agenda and which also address the most promising frontiers of basic research.

Currently, behavioral science research is funded according to a "de facto" agenda that is short term in its perspective and, for the most part, shaped haphazardly by individuals and forces outside the psychological and behavioral science community. The Summit was organized by APS and supported in part by the NIMH, to provide NIMH and other federal research agencies with a long-term, stable approach to funding research and training in the behavioral sciences. However, continued threats to funding tend to divert the focus from long-term goals. Therefore, we respectfully request that the Committee encourage the behavioral research agenda planning effort through a commitment to stable funding for behavioral and social science research within the federal research agencies.

Research Training -- Equally important to the long-term stability of behavioral and social science research is the need to expand the NIMH research training budget. This budget has been diminished in recent years to a point where young investigators will be discouraged from entering disciplines that must rely on NIMH for training support. In constant dollars, for example, the NIMH research training budget has actually declined from $5.8 million in 1960 to a projected $3.8 million in 1990. We propose that NIMH research training be increased to $47.6 million in FY 1991. This increase is urgently needed to offset the decline that NIMH research training support has experienced over the past three decades.

Basic, Brain, and Behavioral Research Division -- Recently, the NIMH Basic Science Division underwent a major reorganization, as reflected by its new title, the Division of Basic Brain and Behavioral Science, or DB3, as it is now known. We believe that this is a laudable step toward broadening the scope of basic research at NIMH, and we urge the Committee to oversee NIMH's future plans for DB3 to ensure (1) that adequate resources are allocated to the division and (2) that there is an equitable distribution of funds among the core research disciplines supported by the division.

## National Institutes of Health (NIH)

The prominent role of behavioral and social factors in disease prevention and health promotion is increasingly being recognized by federal health policy makers. Recently, this role was most clearly articulated before the Governmental Affairs Committee by James O. Mason, Assistant Secretary of HHS, who was reporting on the nation's progress in achieving health goals set a decade ago. Assistant Secretary Mason indicated that of the more than 200 national objectives set forth for promoting health and preventing disease, "the areas of greatest difficulty had their roots in behavioral and social issues, not just biomedical ones, including such issues as teenage pregnancy, low birthweight and illicit drug use."

But this is not news. For the past several years, this Committee has stressed the need for stronger research into health and behavior in legislative reports and hearings on NIH and ADAMHA. We appreciate and agree with your initiatives on this issue.

The Committee has asked NIH to report on its long-term plans for strengthening its behavioral and social science activities. We understand that a planning effort is underway. We urge the Members of this Committee to press for a meaningful response from NIH. Specifically, we recommend that NIH include in its report to Congress a schedule and explicit goals for increasing its health and behavior research from its current level of 3 percent to 10 percent.

## National Institute of Child Health and Human Development (NICHD)

APS is part of the Friends of NICHD, a coalition of biomedical and behavioral research organizations which is recommending an FY 1991 budget of $635.3 million for NICHD. This recommendation reflects the actual cost of funding research on child, adolescent and maternal health needs that Congress has previously requested should be conducted as well as other research that the scientific community feels should and can be conducted.

Specifically, this figure would eliminate the effects of "downward negotiation," and would increase NICHD's funding rate to 40 percent of approved grant applications. Our recommendation also would provide full funding for the existing 53 research centers and allow for seven new centers. Research training would be expanded over the President's budget to allow 110 additional trainees.

As illustrated in the following examples, NICHD administers a multidisciplinary program of basic and applied research using the perspectives of the behavioral and social sciences as well as the biological sciences. We believe these initiatives warrant particular attention from Congress because of their scientific merit, the need to build on basic knowledge in such areas as perception, attention, cognition and human development, and the need for more applied research perspectives on complex issues of human functioning.

Preventable injuries. NICHD has developed a Five-Year Plan that includes initiatives to address the behavioral and social factors associated with preventable injuries in children and adolescents. Such injuries -- poisonings, drownings, gunshot wounds, pedestrian injuries, car accidents -- account for more morbidity and mortality among young people than the next six leading causes combined. NICHD should be encouraged in its efforts to identify children at risk for injury and to examine effective interventions for both children and parents.

Learning disabilities. NICHD's research centers are slated for a 21.6 percent reduction in the FY 1991 budget, representing a five percent further erosion from required FY 1990 cuts. The research centers address some of the most difficult challenges facing the country today, including dyslexia and other learning disabilities which afflict thousands of children and adolescents and prevent them from functioning at their full potential in a complex society. Research aimed at the identification of the learning disabled from birth to age 3 is needed in order to develop early interventions for these individuals.

Day care. A 10-site collaborative effort is now underway to standardize the study of the effects or alternative models of care. Given the high percentage of maternal employment in the United States, we appreciate the sensitivity of such a study and encourage its scientific support.

Behavior and biology. Developmental psychobiology is the study of the interactions between behavior and biology. This field is yielding exciting new information about such areas as learning and cognition, language, and even parenting. In addition, it is now likely that behavioral approaches to Sudden Infant Death Syndrome (SIDS) may provide new insights into this killer of 8,000 babies each year.

Normative research. NICHD also supports normative research on children. This is particularly important among ethnic minority children, since all too often, our knowledge of ethnic minorities is the result of studies of poverty, crime, disadvantaged education, or other aspects of decidedly non-normal development. There is a clear need for research that focuses on the normal development of ethnic minorities.

Child maltreatment. Special recognition should be given to the high quality behavioral work being done by the intramural laboratory of NICHD. We strongly urge the Committee to commend this work, and to encourage its development in new areas, particularly in the direction of the effects of child maltreatment.

## National Institute on Aging (NIA)

As the proportion of the U.S. population age 65 and over continues to grow, NIA's research mission becomes increasingly important in understanding and developing the means to deal with both individual and social aspects of aging. NIA supports research on the effects of behavioral and social factors in the aging process, and in particular, the role of these factors in prolonging the healthy and productive lives of older people.

Particularly impressive is research demonstrating the significance of psychological, behavioral and social factors in delaying morbidity and mortality in old age. For example, the well-known Alameda County Study shows that older people who smoke, are physically inactive, or have poor dietary practices are at higher risk for death than those who do not engage in these behaviors. Even in their advanced years, people can increase longevity significantly by improving their self-care practices. Although the modification of lifetime habits may be thought to be especially difficult, NIA-supported research has shown that older people can successfully modify their health practices using behavioral and social interventions.

Despite such contributions to the understanding and treatment of age-related conditions, NIA's Behavioral and Social Science Research program continues to experience unacceptably low funding rates. In certain funding cycles of FY 90, only the 6th-7th percentile of approved grants were funded. Therefore, we urge the Committee to provide an additional $20 million to fund research that promotes our understanding of aging, health and behavior; and on disease diagnosis, treatment and prevention as well as health promotion. Specific areas of inquiry should include: how older Americans and their families perceive and cope with life stresses, chronic conditions, and disabilities; strategies for promoting health-maintaining behaviors such as self-care or awareness of injury hazards; how sense of personal control and social support improve health and effective functioning; the special social circumstances of older rural Americans that affect health attitudes and behaviors and access to quality care; male/female differences in health behaviors and lifestyles that influence longevity and well-being; health attitudes and behaviors of special populations such as African-American, Asian, Hispanic, Native Hawaiian, and Native American older people; the oldest-old; and retarded or developmentally disabled adults.

Additional areas of research. In addition to studying the relationship between health and behavior, NIA funds research on the cognitive and intellectual functions in aging, focusing on memory, perception, and psychomotor skills. However, we are concerned that current assessment techniques in these areas are developed from studying the general, younger population and therefore do not detect the important functional changes that older people may or may not experience. It is critical that NIA support the development of assessment techniques in older adults. These assessments will yield information that has important implications for employment and training of the older citizen as well as for the effective functioning of older Americans in everyday life.

Another important area for older people is memory research. We know that there are different kinds of memory: retrospective memory is what we use when we recall what we had for breakfast this morning; prospective memory is what is used to remember how to tie our shoes, or to take a pill at prescribed intervals. Research is needed in the latter area in order to develop techniques for ensuring that older people comply with drug regimens and more independently manage other aspects of their health care and living.

Finally, we wish to support NIA's Alzheimer's Disease research, and to suggest an expansion in NIA's investigations of the burden of care faced by the families of Alzheimer's victims. APS urges this Committee to provide additional funds for behavioral and social science research on Alzheimer's Disease.

**National Heart, Lung and Blood Institute** (NHLBI)

Nowhere is the relationship between health and behavior more clear than in coronary, lung, and blood diseases. Members of this Committee may have seen the April 4th front-page *Washington Post* article on the large-scale MRFIT (Multiple Risk Factor Intervention Trial) study which documents the effectiveness of behavioral changes in lowering the risk of heart disease or heart attacks. The behaviors addressed were smoking and diet, and there was medical treatment for high blood pressure.

Other studies, including some which have received support from NHLBI, have shown that changes in diet combined with stress management techniques can result in a reversal of atherosclerosis.

We feel that the NHLBI research portfolio should reflect a balance of basic science and more applied research. A number of non-NHLBI studies have documented the influence of lifestyle factors in achieving positive health results. Given the proven connections, we believe it is the Institute's responsibility to accelerate its activities in this area. Therefore, we request that this Committee ask the NHLBI to report on its activities in health and behavior, and provide a plan for expanding its research portfolio on such topics as the health and behavior in workplace, and evaluation of service programs.

Thank you for the opportunity to provide this statement. We would be pleased to provide additional information to assist you in your deliberations on these important health research funding issues.

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## STATEMENT OF THE COALITION OF EPSCoR STATES

Mr. Chairman and Members of the Subcommittee, we appreciate the opportunity you have given us to submit this statement. The Coalition was formed approximately one year ago to work in support of the concepts embodied in the National Science Foundation's Experimental Program to Stimulate Competitive Research (EPSCoR).

The National Science Foundation established EPSCoR in 1979 for the purpose of developing the capacity of scientists and institutions in eligible states to compete more successfully for Federal research funding from NSF and other Federal agencies. The EPSCoR approach involves a coordinated state-wide planning effort, designed to identify programs which will facilitate the creation of pockets of research excellence within each state. Since 1979, 16 states and Puerto Rico* have been designated by NSF as eligible for participation.

The Coalition was formed to increase awareness of the EPSCoR program, to secure additional funding for it at NSF, and to encourage other agencies and departments of the Federal

*Alabama, Arkansas, Idaho, Kentucky, Louisiana, Maine, Mississippi, Montana, Nevada, North Dakota, Oklahoma, Puerto Rico, South Carolina, South Dakota, Vermont, West Virginia and Wyoming.

government to adopt complimentary initiatives. By this statement we request this Subcommittee's support for initiating an EPSCoR-type initiative at the National Institutes of Health (NIH).

Characteristics of the EPSCoR States.

Presently, Federal research funding is concentrated in relatively few states and regions of the nation. As you can see from Chart I, the 16 EPSCoR states and Puerto Rico, while containing 13% of the United States population, receive only 5.6% of Federal research and development dollars. In contrast, the top five research states, with 27.9% of the population, receive 44.5% of Federal research and development dollars. It is not surprising, therefore, -- in fact it may be related, -- that the EPSCoR states tend to have a per capita income that is lower than the national average and substantially lower than the top five research states. This is shown in Chart II.

The EPSCoR experiment, while funded at only one-quarter of one percent of the NSF budget, was designed as a first step in addressing this disparity. The EPSCoR approach involves the establishment of a state-wide coordinating mechanism to:

-- Identify state and institutional barriers to competitive research

-- Develop a comprehensive improvement plan supported by state and institutional resources.

-- Undertake a merit review of all EPSCoR programs and;

-- Implement the improvement plan focusing on infrastructure improvement, research enhancements and human resource development.

The result has been a significant improvement in state support for research and development in the EPSCoR states. As you can see from Charts III and IV, Federal support as a percent of total spending for research and development at our research universities continues to lag significantly behind both the national average for Federal support and the percentage of support provided to the top five states. On the other hand, state support in the EPSCoR states is twice the national average and over seven times as great on a percentage basis as it is in the state that receives the greatest amount of Federal support.

Initiating an EPSCoR Program at NIH.

Mr. Chairman, it is now time for a serious government-wide, systematic effort to broaden this Nation's research base, and we believe that the EPSCoR approach, as developed and refined by NSF for over 10 years, is the best way to proceed. We are not alone in this view; Dr. D. Allan Bromley, the President's Science Advisor, and Mr. Erich Bloch, the NSF Director, have expressed specific support for having the EPSCoR model adopted by other departments. We would also note that the Association of American Universities (AAU) and the National Association of State Universities and Land-Grant Colleges are both on record in this regard.

Accordingly, we hope that this Subcommittee will consider having the National Institutes of Health make available a small amount of their research funding, perhaps up to $4 million, to states for competitively-awarded EPSCoR-type grants. This amount of money could support a number of planning grants for states to assess their potential in areas of biomedical research and to develop comprehensive plans to develop this potential. For those EPSCoR states that have already made progress in this area, there could be a small number of larger implementation grants that would support research enhancement, infrastructure improvement and/or human resource development in biomedical research and related sciences.

Conclusion.

In 1979, NSF, faced with a requirement in its charter that it "avoid undue concentrations of research" initiated EPSCoR in an effort to broaden the distribution of its research funds. As developed over the last decade by NSF, this state-based model has proven effective; two out of the last three engineering research centers awarded by the Foundation went to institutions in EPSCoR states.

We in the Coalition believe that this proven model should be extended to other departments and agencies that fund research, including the NIH. With the support of this Subcommittee, we are confident that the breadth of the research enterprise funded by NIH will be improved and that a significant enhancement of our human resource potential in the biomedical area will result.

Chart I

## COMPARISON OF POPULATION AND FEDERAL R & D $$ AS PER CENT OF THE U.S. TOTAL

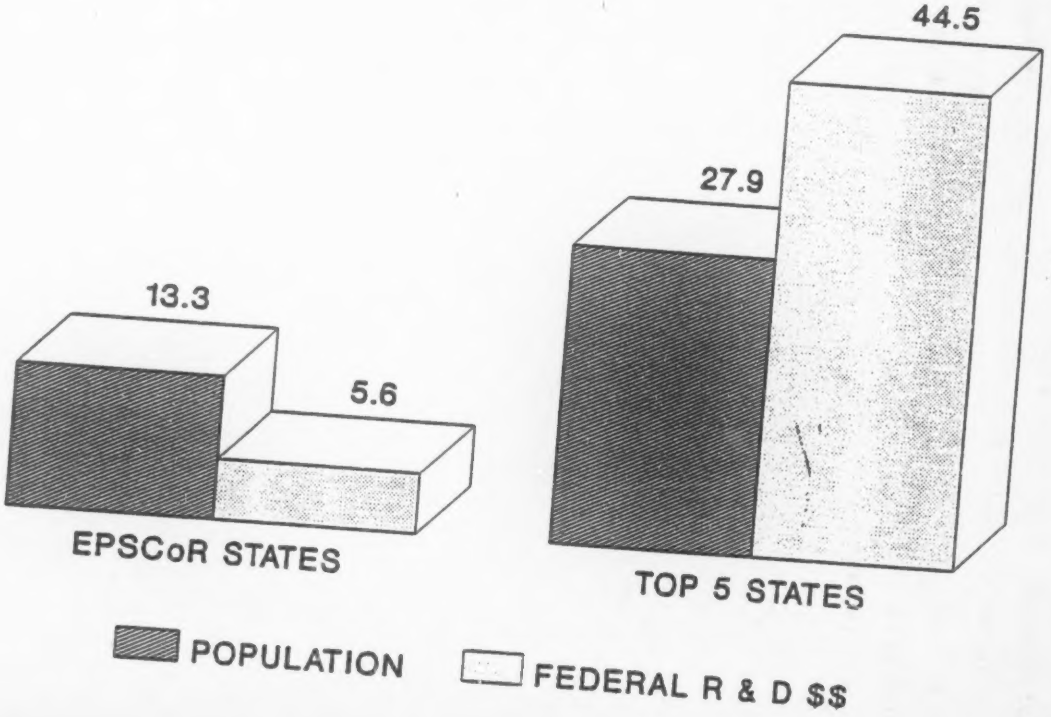


Chart II

# PER CAPITA INCOME, 1988
# PER CENT OF NATIONAL AVERAGE

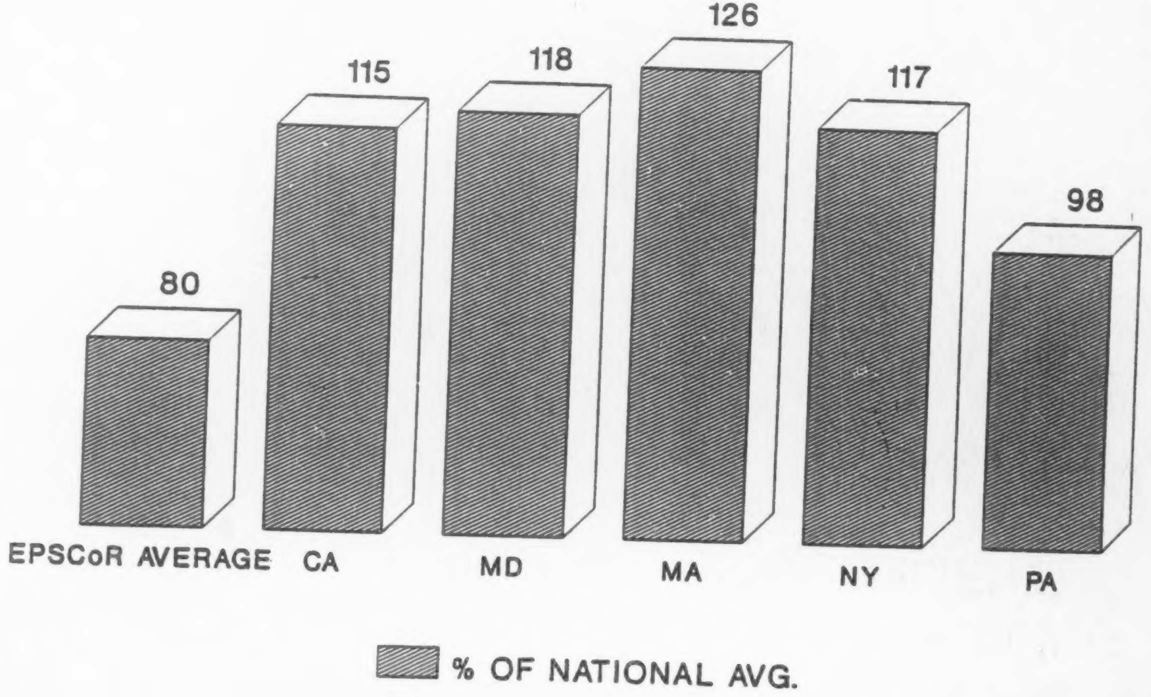


Chart III

## PER CENT OF TOTAL 1988 R & D SPENDING PROVIDED BY FEDERAL GOVERNMENT

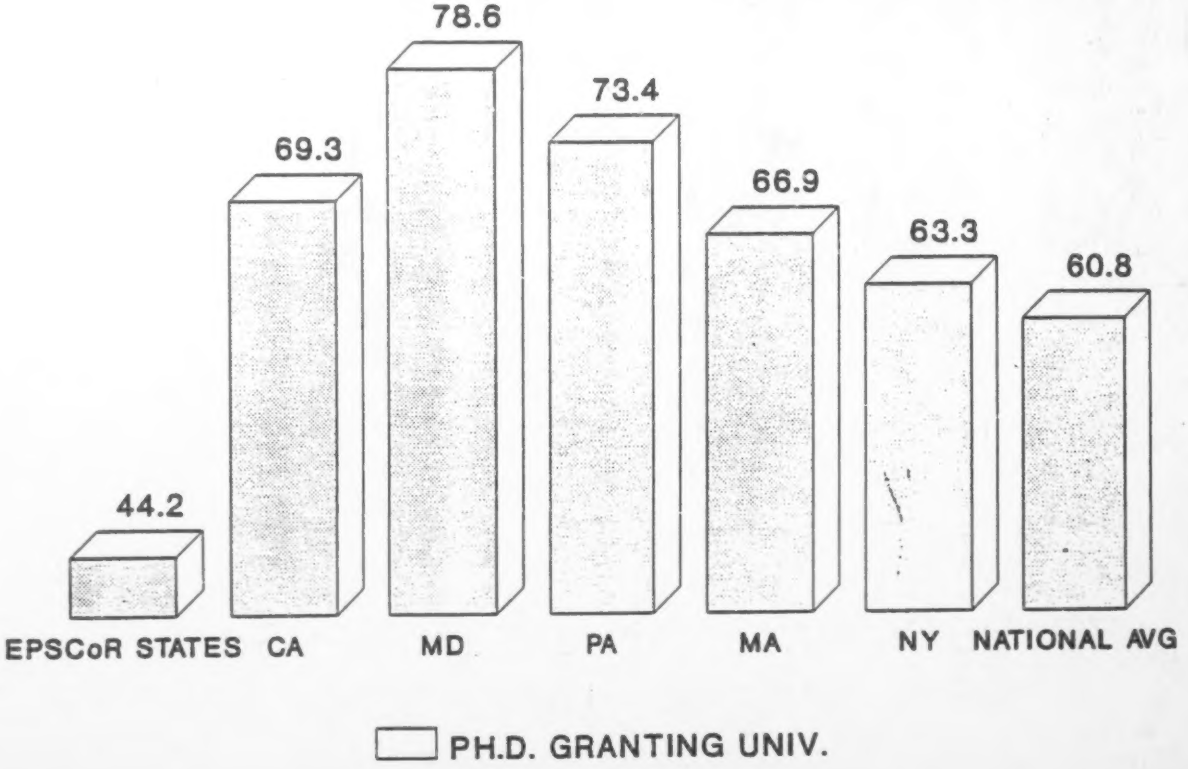
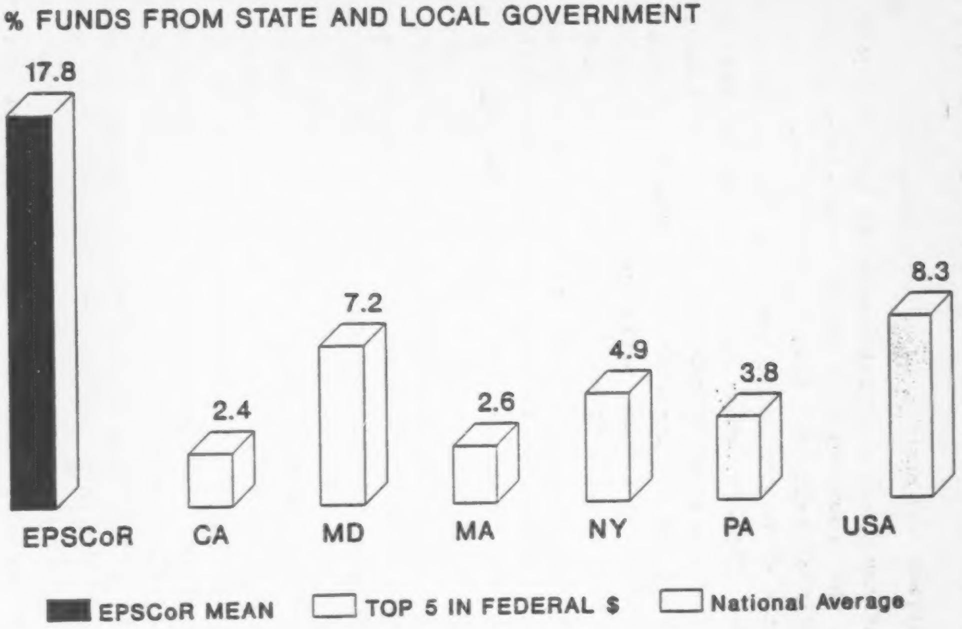


Chart IV

## RESEARCH AND DEVELOPMENT SPENDING BY DOCTORATE-GRANTING UNIVERSITIES FY 88



Source: National Science Foundation

## STATEMENT OF THE ASSOCIATION OF PROFESSORS OF MEDICINE

Mr. Chairman and Members of the Subcommittee:

The Association of Professors of Medicine (APM) is pleased to have the opportunity to present our views and recommendations on the fiscal year (FY) 1991 appropriations for the National Institutes of Health (NIH) and other Public Health Service programs. The APM, which represents the chairmen of departments of internal medicine at the 126 U.S. medical schools, views the vitality of the NIH research enterprise as not only one of our organization's paramount public policy goals, but also as one of our nation's vital national resources. It is in this spirit -- that the NIH is the critical component of America's academic biomedical research effort and an embodiment of the creative spirit of our nation -- that the APM offers this statement.

Members of the APM and their departments are major actors in the research enterprise supported by the NIH. In FY 1989, departments of medicine themselves approximately $1 billion in extramural research funding from the NIH. If NIH research grants awarded to medicine departmental faculty through large academic medical center teaching hospitals are taken into account, the level of NIH extramural funding received by departments of medicine approaches 50 percent of the NIH total. A large number of the most important breakthroughs in the treatment of disease and the advancement of biomedical science in the last four decades have come from faculty of departments of medicine. Thus, it is clear that APM members and their faculty play a significant role in the conduct of biomedical research in the U.S., and have a major stake in working towards ensuring that the NIH system continues to flourish.

The Association's statement will concentrate on four areas of the NIH research system: the numbers of new and competing renewal awards funded by the NIH; the impact of arbitrary cuts -- euphemistically known as "downward negotiation" -- on the research enterprise; the importance and level of research training supported by the NIH; and, the importance of balance in training supported by the NIH; and, the importance of balance in the system between basic and clinical research.

Competing Awards. The number of competing research project grants (RPGs) awarded each year by the NIH is a significant measurement of the current status of the research enterprise. In 1980, the NIH awarded just under 40 percent of the competing awards approved for funding through the peer review process (a figure known as the award rate), for a total of just over 5,000 competing RPG awards. As recently as four years ago, the number of competing awards was over 6,400. In the current fiscal year (FY 1990), however, the number of competing RPG awards has fallen to under 4,700 and the award rate has declined to less than 25 percent. If the Subcommittee agrees that the level of new awards is a litmus test for the health of the NIH, than the patient is ill and in need of therapy.

The NIH budget submitted by the Bush Administration would increase the number of competing RPGs to just under 5,100 for FY 1991. While this appears to be a welcome trend, a closer examination of the funding earmarked for new awards reveals a continuation of past policy of spreading limited dollars over a larger number of grants. Specifically, in order to fund the 5,095 new awards called for in the Administration's budget at the requested level, a cut of over 14 percent on each award is estimated by the NIH to be necessary.

It is significant to note that if the increases for the human genome initiative and AIDS research are removed from the proposed NIH budget, the number of competing awards would be only 4,800. To be blunt, there is no use in training people for careers as researchers if there is not going to be NIH research grants available to them at the beginning and throughout their careers. Competing awards must remain the backbone of the NIH enterprise, as they are the backbone of science.

Arbitrary Cuts in Research Grants. The continued advocacy and use of the so-called downward negotiation by the Administration and the NIH has done great damage to the NIH system. While the goal of this mechanism -- providing a greater number of awards -- is a proper one, to believe that arbitrary reductions from peer review recommended levels averaging 10 percent over the last four years will not do harm to the system is naive. These cuts on RPGs, as well as research center awards which last year averaged nearly 20 percent from recommended levels, ask investigators to undertake their research as demanded by science and as recommended by colleagues, but with less funding. Not only will this modus operandi hinder the advances made through biomedical research against the deadly diseases now afflicting mankind, but it will also further discourage promising young physicians and scientists from pursuing careers in research. The Subcommittee and Congress as a whole must make a strong statement that NIH research awards must be fully funded at levels recommended throughout the peer review process.

Research Training. In the vein of attracting the best and brightest young students to careers biomedical sciences, the research training funds provided by the NIH through the National Research Service Award (NRSA) program are critical. On a positive note, the Association is pleased that the number of institutional and individual training positions funded by the NRSA program has grown over the past two years to a current level of 11,755 positions. This total is within the range of recommendations for training positions made by the National Academy of Sciences. The Administration's FY 1991 budget request earmarks funding for approximately 12,020 training positions, continuing the positive upward trend in support for NIH research training.

The importance of research training was recently highlighted in a report from the National Research Council (NRC) entitled "Biomedical and Behavioral Research Scientists: Their Training and Supply." The importance of research training was eloquently stated in a paper commissioned by the study prepared by Dr. Lloyd Smith of the University of California - San Francisco:

> The basic purpose of science policy, after all, is not to employ scientists but to ensure that the nation's goals in research and education be met...For science itself, [research training] furnishes useful workers who contribute to the completion of the investigative projects in which they are engaged. Of equal
>
> importance, the [trainee] benefits from learning further about scientific method and thereby is better prepared to evaluate medical progress...

The NRC report also cites the continuing interface between basic science and clinical medicine; it is now the rule rather than the exception that advances in biology are paralleled by related advances in clinical application. Thus, it is this "clinical research" that applies the results of the work of the basic research to the fight against the deadly diseases afflicting millions each year. A great deal of clinical research is conducted by the physician/scientist -- an individual trained in medicine who has also pursued study in one of the fields of basic biology. Data suggests that the numbers of physician/scientists in training is inadequate relative to the demands dictated by the future needs of science. The APM urges the Subcommittee to recognize the need for increased training of physician/scientists through the NRSA program, in order to obtain a more equitable balance in the type of personnel trained.

Balance in Basic and Clinical Science. The need for balance also exists in the overall NIH research grant program. Similar to the importance of having adequate numbers of both M.D. and Ph.D. investigators engaged in its training program, the NIH must also work towards achieving a more equitable ratio of clinical to basic research projects in the extramural awards program. This ratio should be consistent with the need to translate emerging discoveries in basic science from "the bench to the bedside."

The NRC report cited previously indicates some disturbing trends: the number of competing NIH grants awarded to physicians (who, necessarily, are the most likely and most qualified to perform clinical research) fell from 37 percent of the total competing awards to 27 percent from 1977 to 1987, while during the same period the percentage of total awards made to basic scientists has gone from 64 to 72. Moreover, the report shows that the total number of physicians engaged primarily in research declined by nearly 30 percent from 1985 to 1987.

This information should not be construed as meaning the APM does not favor a vigorous basic science research effort funded by the NIH -- quite the contrary; the Association is simply advocating for greater balance between the levels of NIH funding for basic and clinical investigation. While it is true that there has been tremendous progress in research in such fields as human genetics and microbiology, the discoveries wrought through this investigation will not be allowed to fully benefit mankind if there is not research into the related clinical application.

APM Recommendation. For FY 1991, the APM joins with the other members of the Ad Hoc Group for Medical Research Funding in recommending an overall NIH appropriation of $9.237 billion, including funds for AIDS. An appropriation of this magnitude would fund approximately 6,000 new and competing renewal awards for the upcoming fiscal year at their full peer review recommended levels. Funding for competing awards at this level would begin the process of restoring stability to the NIH research enterprise. The Association's recommendation also includes $770 million for the NIH research centers program -- a level which assumes current services plus an additional $75 million to restore the 15-20 percent post-peer review cuts taken on centers grants over the last three years. The APM supports the level of training called for by the Administration, 12,020 NRSA positions; however, our recommendation includes funding for training over that called for by the President in order to support full trainee stipends. Lastly, the APM urges the Congress to provide $150 million for extramural research facilities construction in the FY 1991 appropriation. The state of our research laboratories has deteriorated markedly in recent years and are badly in need of renovation.

The APM also urges that the Committee reject the Administration's proposal to zero out funds for the categorical health manpower training programs under Title VII of the Public Health Service Act. In particular, the Association urges funding for the General Internal Medicine and Pediatrics Residency Training program at $25 million for FY 1991, the full amount authorized.

The APM thanks you for the opportunity to present its views. Please call on the Association whenever we may be of assistance.

## STATEMENT OF THE ENDOCRINE SOCIETY

Chairman Harkin, and Members of the Subcommittee, my name is Jack Gorski, Ph.D., President Elect, Endocrine Society, it is truly my distinct honor to appear before you today to discuss the welfare of the National Institutes of Health and represent the Endocrine Society, which is made up of over 6,000 Endocrinologists, physicians and investigators, across the Nation. I am a professor of Biochemistry at the University of Wisconsin where I teach as well as direct a research program on the mechanism of action of estrogenic hormones. I would like to present a few brief comments, and request that you would include my complete statement in the record.

This year I come before you to lend my support for increasing the NIH budget in order to increase the number of research project grants which are supported by the National Institutes of Health. Over the past 100 years, the NIH has been privileged. Congress took the charge in assuring that Americans would be at the forefront of medical advancement -- that we would set the pace for the rest of the world to follow. Surely, the work of this distinguished Subcommittee has served to foster this noble cause and as a teacher and researcher, I commend you in your efforts. However, in the same breath, I must issue a pessimistic viewpoint. As I am sure you are aware, our past Federal research investment is being threatened. We have failed to keep up with inflation, and now, after a decade of insufficient funding, we find ourselves unable to fund even half of the meritorious research.

The R01 pool, investigator initiated research, is the cornerstone of the medical research advancement in this country, without it, our scientific advancement will be crippled. However, both the NICHD and the NIDDK will only be able to fund approximately 21% of the approved research grants. This means that almost 80% of the meritorious research will lay by the wayside unless the additional funds are made available.

Our inability to adequately support research is a direct result of research opportunities out pacing funding. This will ultimately be disastrous for our research enterprise. Year after year we subject our research project grants to devastating **"downward negotiations"** which essentially serve as budget cuts. Under the FY 1991 Administration Budget, the NIH estimates that downward negotiations will be in the range of 14% - 20%. The two basic Institutes which conduct endocrine research (although almost all of the Institutes including NCI conduct some form of endocrine research) are the National Institute on Child Health and Human Development and the National Institute of Diabetes, and Digestive and Kidney Disorders. It is estimated that they will have downward negotiations of approximately 14% and 11% respectively, for research grants. Centers in these two instances would suffer 21.6% and 30% downward negotiations respectively.

If we continue to stretch the Federal research dollar we must also recognize that at some point, it will no longer be feasible to continue to support our research program.

As I am sure you are aware, scientific advancement often happens when we least expect it. If we continue to fund such a small percentage of our worthy research, we may never come to realize our expectations and certainly, opportunities are lost each time we turn an investigator away. The opportunity for a successful research career for many talented young investigators has become virtually impossible.

Because of the fine work of this Subcommittee the research community was fortunate to restore the number of training grants that the NIH was able to fund. However, if we are failing to fund the grants submitted by these young scientists mentors, and as they watch as well-respected members of the research community fail to obtain funding from the NIH, it is unlikely that we will be able to entice young investigators into the field.

This year, the Ad Hoc Group for Medical Research is recommending that the NIH receive a budget of $9.2 billion. This is approximately $1.4 billion over the President's FY 1991 Request. This would allow for a 30% - 33% award rate -- fully funded. The Endocrine supports this figure as a worthy starting point. We need to bring our Federal research program back to its premier status experienced over a decade ago.

We are witnessing a time when an increasing number of countries are investing more into medical research than the U.S. We must be committed in our investment in the future. The health of our Nation and the world depends upon the foresight of the Congress and the support of the American people. As an endocrinologist, I have had the opportunity to see science advance in a great many ways.

This year both the House and the Senate have introduced legislation which would institute contraceptive and fertility research centers across the Nation. The NICHD would be primarily responsible for the conduct of these centers, and yet, without funding, these centers would only serve to take away funds from individual investigators and increase the hardship which is being experienced by the NICHD. The Endocrine Society is calling upon this Subcommittee to assure that ample money be placed in the programs which will ultimately yield a significant benefit for our Nation.

Another area of research with which the Endocrine Members are involved is that of diabetes research. It is estimated that diabetes costs this nation $20.4 billion direct and indirect costs annually. In FY 1990 it is estimated that NIH will invest $252 million in diabetes research, NIDDK will fund approximately $150 million of that total, just a small fraction of what this disease costs us annually.

Through our Federal research investment the advancements have been made. One example of this is our understanding of the gene structure of the number of hormones and their receptors. This will lead to future treatments using human hormones produced by recombinant DNA technology. The use of erythropoietin is an example of such a development.

An issue which is of great concern to the Endocrine Society is that regarding the use of animals for research. Only through animal research are we able to find models for which to test potential life saving treatments. The benefits which have been provided to this Society as a result of animal research is experienced daily. It is essential that sufficient funds be provided to the intramural and extramural programs in order to assure the highest quality care must be given to these animals if we are to act in a civilized and human manner as well as for the purposes of conducting top notch research. We appreciate and need your continued support in this area. Your support of the legislation introduced by Senator Heflin is an example of the positive steps Congress is willing to take to assure that animal research continue at a high level.

Research is an investment in our future. For every $1 spent on medical research, $13 is saved in lost wages, health care costs and productivity. Currently, we spend $2,000/per person on health care expenditures, and only $35/per person on medical research. If we make the initial investment in research a priority, we will not only find savings in the end, we will have provided for a more productive, healthier society -- a product which cannot be properly appraised.

I would like to thank the Subcommittee for their patience and consideration of my remarks. The future of our Federal research programs rests with the wisdom of the Congress. Your efforts on behalf of the NIH are greatly appreciated by the members of the Endocrine Society. If we can provide any information regarding specific endocrine research related issues or funding needs we would be more than happy to provide that information to you. This concludes my remarks, and would be happy to answer any questions you may have.

# NATIONAL INSTITUTE OF ARTHRITIS, MUSCULOSKELETAL AND SKIN DISEASES

## STATEMENT OF THE LUPUS FOUNDATION OF AMERICA

The Lupus Foundation of America, Inc. (LFA), a national voluntary health agency, represents those with lupus, their families, friends, and concerned others. We welcome the opportunity to submit this testimony for FY 1991 appropriations for the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS). The LFA deeply appreciates the support Congress has historically given the National Institutes of Health (NIH). This continued committment to biomedical research has, within the last twenty years, drastically reduced the high mortality rate of those with lupus. Now, with earlier diagnosis and more effective treatments, most patients are living longer, and leading more productive lives.

Systemic Lupus Erythematosis (SLE) , or lupus as it is commonly known, is a chronic inflammatory disease of the connective tissues. Instead of serving its normal protective function, the immune system forms antibodies that attack healthy tissues and organs, in effect causing the body to become allergic to itself. There are two major forms of lupus. Discoid lupus affects only the skin, causing a rash and lesions usually across the face and on the upper part of the body. Systemic lupus can attack any body organ or system, including the joints, kidneys, brain, heart, and lungs. This more severe form of the disease can be life-threatening.

It is estimated that as many as half a million Americans suffer from one or the other type of lupus, making it more common than leukemia, muscular dystrophy, or multiple sclerosis. Lupus affects women nine times more often than men, with the onset most often in their 20's to 30's when they are in their most productive years. The incidence of lupus is three times more prevalent in Blacks, Hispanics, some Asian groups and certain American Indian tribes.

Researchers supported by NIAMS have made recent progress in the development of new tests to diagnose lupus and to measure disease activity. This is a major step forward, as even a mild case of lupus can become serious and potentially fatal if not diagnosed early and properly treated.

For example, researchers have found that successive measurements of a specific blood factor may be a useful tool to predict flare-ups of the disease. Other research has shown that measuring elevated levels of a certain anti-histone (a type of nuclear structure protein) antibody provides a sensitive and specific marker for a type of reversible lupus that can occur after taking the arrhytmia drug procainamide.

Because lupus affects women of childbearing age, there has been common belief that pregnancy causes the disease to worsen. Therefore, many physicians prescribe prophylactic prednisone therapy for lupus patients who become pregnant. In recent studies, however, researchers have found that lupus does not worsen during pregnancy and that preventive prednisone therapy is unnecessary. This is a significant finding, both on behalf of the mother's well-being as well as her developing fetus'. Other studies have shown that normal, healthy women who have recurrent miscarriages may also have an underlying connective tissue disease such as lupus. Researchers found that some of these women had high levels of antiphospholipid (APL) antibodies in their blood. Further research is needed in this area to find out if intervening therapy is indicated.

Experts on lupus are continuing to improve previously developed forms of treatment as well as to develop new ones. The drugs most commonly used to treat lupus include corticosteroids such as prednisone and nonsteroidal anti-inflammatory drugs such as aspirin. The fear of kidney disease (nephritis) is universal among patients with lupus. For severe lupus kidney disease, NIAMS researchers are using chemotherapy drugs such as cyclophosphamide as a way of suppressing the immune system. They have demonstrated that high doses of the drug administered periodically (pulse therapy) can reduce progression to kidney failure in patients with lupus nephritis. Although these treatments have enabled lupus patients to live, the long-term side affects are still too toxic to be acceptable.

Eighty percent of lupus research is conducted through NIAMS. We are, therefore, respectfully submitting to Congress a request that the NIAMS budget be increased by $50 million. This will give NIAMS parity with the other NIH institutes in terms of the percentage of approved grants funded (increasing it from 16.6% to 28%), enable 60 additional researchers to be trained, support more of the urgently needed clinical trials, and add $7 million to the intrammural research programs. This increase to NIAMS would place it on a proportionate footing with the other institutes, as well as help protect and expand the scientific advances acheived to date.

Victims of lupus look with hope to the biomedical research currently underway and that which is projected for the future. For them, solving the mysteries of lupus depends on identifying the hard scientific facts of cause, control, cure, and, ultimately, prevention of lupus. This request is not only made for humanitarian reasons, but also for the socioeconomic impact of this chronic, debilitating disease. All those with SLE are looking to Congress to help them continue to be active and productive members of society.

## STATEMENT OF THE UNITED SCLERODERMA FOUNDATION, INC.

My name is Annette Scalone, a scleroderma patient and a member of the United Scleroderma Foundation, Inc. Thank you for affording me the opportunity to submit this written testimony on behalf of our membership.

Scleroderma literally means "hard skin", and manifests itself in two forms. The localized form, occurring mostly in children, affects the skin and underlying tissue and bone. The systemic form also affects internal organs, i.e., heart, lungs, gastrointestinal tract, and kidneys. Oxygen, tube feeding or dialysis may be required in severe cases. The face can be drawn tight giving a mask-like effect, and oral hygiene becomes a serious problem as the mouth will not open properly. Skin on the hands also tightens with resulting crippling, and patients are very prone to infections. Circulation is impaired and cold or stress brings on a spasm of color changes and total numbness in the extremities. Ulcerations occur on the fingers and are difficult to heal, while other infections are caused by a build-up of calcium protruding through the skin. Fear of gangrene and amputation is a continual worry.

Six years ago, I was up at 6 a.m., did an hour of aerobics, attended a city council meeting at 8 a.m., put the finishing touches on a fund raising event for a professional theatre company, arrived home at 3 a.m., packed my bags, showered, and was on a plane by 5 a.m. bound for Greece. I arrived in Greece with a bottle of champagne, and several new friends. I traveled to Turkey and Egypt, rode camels around the pyramids, visited some Greek Islands, and fell in love with a man from Georgia. Five months later I got married, and two months after that I was diagnosed with Raynaud's

Disease, a condition in which there is decreased blood flow to the body tissues.

My life changed over night. With arms and legs that go completely numb from the elbows and the knees down, and two fingers with gangrene, it was impossible for me to continue working. My life was reduced to being wrapped in an electric blanket with mittens on my hands while I tried not to let the panic get the better of me. (Any strong emotion; happiness, sadness, anger, joy constricts the arteries and veins reducing blood flow to the limbs.) During the summer, I tried to volunteer my time to a nonprofit group in the community, resume normal household tasks, and make some friends only to find my efforts defeated by air-conditioning. Two more winters passed; I still could not adjust.

My husband moved me to Florida, and for the first time in three years I could get out of bed, walk to the bathroom, and take a shower all without turning painfully numb. Sheer heaven! Within two weeks, I was back in the fund raising business. The next eight months I fought to stay healthy, but the Raynaud's and my inability to fight off simple infections prevailed. The Raynaud's progressed to its present stage; if I walk from a room temperature of 84 degrees into a room temperature of 78 degrees my limbs turn numb.

My husband's work brought us to Maryland, where for the first time I was diagnosed correctly with scleroderma, of which Raynaud's Syndrome is a symptom. This past winter I spent two out of four weeks sick in bed.

The immune system, the vascular system and connective tissue metabolism are known to play a part in this disease, but there's so much we don't know. The Congress has shown immense generosity to the National Institutes of Health (NIH) and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) in the past. Congress allocated the funds, and today Scleroderma researchers have a new animal model, the tight skin mouse, for studying the increased accumulation of collagen in the skin.

This is one of many accomplishments motivating the Coalition's request for an additional $50 million to the FY 1991 NIAMS budget. If NIAMS can achieve parity with other NIH institutions by increasing the number of approved grants funded, research utilizing the new animal model can begin.

This country has the talent, the facilities, and even the time to save its most precious resource, its people. People like me, who were once part of the mainstream, paying taxes and actively participating in the community. We are already educated, already employable, already an asset to our communities, already helping those less fortunate than ourselves were it not for our diseases. Congress has the power to help us remain part of the solution. A $50 million increase in the NIAMS budget would increase funding from 16% to 28% of approved grants; train 60 additional researchers; support urgently needed clinical trials; fund four new centers; and increase the intramural research program by $7 million. If we do not remain part of the solution, we become part of the problem, another burden on the tax-payers. Eventually, we will not have this choice. Eventually, we will be too sick to care.

Thank you for allowing me the opportunity to present this testimony.

## STATEMENT OF THE COALITION FOR SKIN DISEASE

MY NAME IS LADONNA WILLIMAS. I HAVE TWO CHILDREN WHO SUFFER FROM THE DISEASE ECZEMA. ALTHOUGH NOT A KILLER, NOR A WIDELY HEADLINED DISEASE, ECZEMA IS A SOCIALLY TERMINAL DISEASE. ECZEMA CAUSE A RASH AND SORES ALL OVER THE BODY. YOU OBVIOUSLY LOOK DIFFERENT. YOUR PEERS NOTICE, AND YOU BECOME AN OUTCAST. IT HURTS WHEN PEOPLE MAKE FUN OF THE WAY YOU LOOK, OR PULL THEIR CHILDREN AWAY, OR REFUSE ENTRANCE INTO THE COMMUNITY SWIMMING POOL IN FEAR THE ECZEMA PATIENT IS CONTAGIOUS. PLUS, IT ITCHES ALL OF THE TIME. LIFE IS SO RESTRICTED. TEMPERATURE CHANGES AND CLOTHING, DIET, MEDICATION, THICK GREASY CREAMS AND OINTMENTS ARE ALL A PART OF DAY TO DAY LIVING. SLEEPLESS NIGHTS WITH BANDAGED HANDS, AND STILL THE ITCH, ANOTHER PART OF THIS PAINFUL SCENARIO.

SOME INDIVIDUALS THINK THIS IS A SIMPLE PROBLEM YOU OUTGROW. MY OLDEST DAUGHTER OF 13 YEARS HAS BEEN AFFLICTED SINCE EARLY CHILDHOOD. SHE HAS SUFFERED SEVERE EMOTIONAL DISTRESS THROUGH THE MOST CRUCIAL YEARS OF HER LIFE, WHEN BEING PART OF A GROUP MEANS SO MUCH. MY SON, 4 1/2 YEARS OLD WAS BORN WITH SKIN RASHES, AND HAS PROGRESSIVELY GOTTEN WORSE. GROW OUT OF? MAYBE A FORTUNATE FEW. LESS SEVERE? AT TIMES, FOR WHICH WE ARE VERY GRATEFUL. FOR MOST HOWEVER, ECZEMA IS A LIFE LONG CYCLE OF SUFFERING.

THANKS TO FUNDING TO THIS POINT, RESEARCHERS ARE LEARNING MORE ABOUT HOW OUR SKIN IS MADE. THIS RESEARCH MAY SOON LEAD US TO A BETTER UNDERSTANDING OF THE DISEASE PROCESS. OUR ULTIMATE GOAL HOWEVER, AND MY OWN FERVENT HOPE, IS TO FIND A CURE OR PREVENTIVE MEASURE FOR THE DISEASE. RESEARCHERS HAVE FOUND THAT FOOD ALLERGIES PLAY A ROLE IN ECZEMA. 25% OF CHILDREN WHO SUFFER FROM ECZEMA

HAVE CONCURRENT FOOD ALLERGIES. APPARENTLY, THE INGESTION OF A FOOD ALERGEN STIMULATES THE SKIN MAST CELLS TO RELEASE HISTAMINE AND WHITE BLOOD CELLS TO RELEASE A FACTOR WHICH CAUSES SKIN ERUPTIONS, ATOPIC DERMITITIS, OR ECZEMA. THIS LINK HOWEVER NEED TO BE EXPLORED FURTHER. RESEARCHERS HAVE LEARNED ALOT ABOUT ECZEMA IN THE PAST FEW YEARS, BUT THE SEARCH FOR A CURE STILL LIES BEFORE US. I'VE BEEN TOLD THAT 1 OUT OF EVERY 5 CHILDREN ARE AFFECTED WITH ECZEMA, AND THAT MANY RESEARCHERS CONSIDER IT A HEREDITARY DISEASE. HOWEVER, NEITHER MY HUSBAND NOR I, NOR ANYONE ELSE IN OUR IMMEDIATE FAMILY HAS ECZEMA, AND YET 2 OUT OF MY 3 CHILDREN ARE AFFECTED BY THIS CONDITION. THIS IS MY OWN PERSONAL REASON FOR SUPPORTING THIS REQUEST FOR ADDITIONAL FUNDING FOR RESEARCH. I AN HERE TODAY HOWEVER TO REPRESENT THE ECZEMA ASSOCIATION FOR SCIENCE AND EDUCATION. WE'VE JOINED THE NIAMS COALITION IN THIS ENDEAVOR. WITH YOUR HELP IN PROVIDING THE CRITICAL FUNDING NECESSARY, RESEARCH CAN BE ENCOURAGED, MORE QUESTIONS ANSWERED, MORE PROBLEMS SOLVED, AND LESS CHILDREN WILL SUFFER. IN ADDITION, EMPLOYEE ABSENTEEISM DUE TO THE MANY OCCUPATIONAL SUBSTANCES THAT EXACERBATE THE ECZEMA DISEASE, WILL BE REDUCED.

THE BENEFITS FROM THE ADDITIONAL RESEARCH FUNDING WILL ALLOW ME TO ASSURE MY CHILDREN THAT THEIR CHILDREN WILL NEVER HAVE TO WORRY ABOUT SKIN DISEASE.

I THANK THE COMMITTEE ON BEHALF OF THE COALITION FOR SKIN DISEASE, NIAMS, AND THE ECZEMA ASSOCIATION FOR YOUR CONCERN FOR OUR FUTURE GENERATIONS. I'LL BE HAPPY TO ANSWER ANY QUESTIONS YOU MIGHT HAVE.

# STATEMENT OF THE FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC.

I am Frances McHugh, the grandmother of a five year old boy with Epidermolytic Hyperkeratosis -- one of the very bad types of Ichthyosis. I am presenting this written testimony as a volunteer and concerned grandparent on behalf of the Foundation For Ichthyosis And Related Skin Types (F.I.R.S.T.)

My concern is the National Institute of Arthritis, Musculoskeletal and Skin Diseases of the National Institute of Health. First of all, I want to sincerely thank Congress for creating this new institute. It is the light at the end of a long dark tunnel. I feel overwhelming gratitude that, finally, people with skin problems have been heard. But it must not stop there. I am asking you to, please, increase the budget of NIAMS for the next fiscal year by Fifty Million Dollars. This Fifty Million will not put NIAMS ahead of any other group but will just put NIAMS on comparable footing.

You probably have no knowledge of Epidermolytic Hyperkeratosis but you must have had a blister on your foot at some time. I am sure you found it very, very painful to walk. Can you imagine what it is like to have eight blisters on each foot, your soles crusted with a half inch of hard dry skin that will not come off (and have blisters under the hard skin) and the rest of your legs and body full of dry scales. This is Epidermolytic Hyperkeratosis -- only one of the dreadful skin conditions that are all part of Ichthyosis.

I know that in the last year there were grants for skin research that went unfunded. This is heartbreaking to me. Actually 83% of approved NIAMS research grants go unfunded. 17% funded grants is really not very much. Some helpful projects have been started but more money is needed. Young researchers will not go into this field if there is no money to support their research. They will look for a better funded field. I look at my grandson -- whose skin all came off when he was born -- and who has struggled with this skin condition for his entire five years -- and I really beseech you to increase the budget for NIAMS by the Fifty Million Dollars. Just put NIAMS on an equal footing with the other institutes.

Again, I want to thank Congress for creating the National Institute of Arthritis, Musculoskeletal and Skin Diseases. This is a fantastic "first step" but it must be kept funded to do the job it can -- and will -- do. The entire membership of The Foundation For Ichthyosis and Related Skin Types wholeheartedly supports NIAMS in their request for this Fifty Million Dollars funding. We all have great hope for the future and know we can count on our elected officials to keep that hope going. We must not take a step back. NIAMS needs that money to keep going forward.

# STATEMENT OF THE AMERICAN ACADEMY OF ORTHOPAEDIC SURGEONS

I am John B. McGinty, M.D., President of the American Academy of Orthopaedic Surgeons. I am also Chairman, Department of Orthopaedic Surgery at the Medical University of South Carolina.

I am pleased to appear before you today to present the Academy's position on the need for continued and, hopefully, expanded funding of research on the musculoskeletal system at the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

The musculoskeletal system provides the structure and motors enabling the human body to move about and function in that remarkably coordinated way that we all take for granted. It is composed of bones, linked together by complex joints, and activated by a highly sophisticated system of muscles, controlled by the nervous system.

These activities of bone--growth, changes, repair, and regeneration--are often taken for granted, since bone is commonly regarded as a dead inert tissue. In actuality, this skeletal struture called bone is in dynamic equilibrium with the rest of the body, exchanging chemicals and consistently being remodeled. This miracle is accomplished by a complex biochemical and physiological process-- a process that is constantly being further understood as research technology progresses. Today it is at the cellular level where the action is. It is only by understanding what is happening in the cell that we can logically approach many of the problems encountered in repairing the diseased skeleton.

These bones are covered at each end by another tissue with unique abilities called cartilage. This tissue through its ability to selectively retain fluid allows extraordinarily smooth motion while maintaining a toughness that resists the stresses that we humans place on our joints. Again it is through repeated investigation at the cellular level that we understand and can highly influence the behavior of live tissues.

As I am sure you are aware, Mr. Chairman, diseases of the musculoskeletal system rank among the most common causes of pain, and disability. In addition to the toll they exact in human suffering, the economic impact of these disorders exceeds $65 billion annually, when measured in terms of the added costs of medical care and lost productivity.1/

On an annual basis more than 40 million people suffer from bone and joint disorders, fractures, and injuries of the tendons and ligaments; approximately 37 million Americans suffer from arthritis, a disease that encompasses more than 100 different disorders of the joints and connective tissues, including osteoarthritis, rheumatoid arthritis, systemic lupus erythematosus, gout, and ankylosing spondylitis and others. Numerous others are afflicted with bone cancer, cerebral palsy and osteoporosis.

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1/ The Frequency of Occurrence, Impact, and Cost of Musculoskeletal Conditions in the United States. Troy L. Holbrook.

Congress wisely recognized the severity and magnitude of these diseases when it created a separate National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). This new institute, with the help of this subcommittee, is providing for a highly focused research program. Although much has been learned about the symptoms and the progress of these diseases and disorders and their management, medical science has yet to discover cures for them.

Scope of Research

The research opportunities in the NIAMS are as varied as the diseases it is attempting to learn about. The field of orthopaedic research supported by the NIAMS includes:

- basic and clinical studies of normal bone, bone growth, and bone metabolism; including investigation of cellular behavior;
- bone and joint diseases, injury, and repair;
- therapies such as joint replacement, and bone and cartilage transplantation to treat these diseases.

Research Advances

Basic research is the lifeline of improved patient care. Each new bit of information, added to the previously existing scientific data base, contributes to clinical advances and the alleviation of human suffering.

Treatment of musculoskeletal disease has dramatically changed over the past 15 years, as a result of improved knowledge of the basic nature, causes and natural history of the disease processes. New technologies involving diagnostic and treatment modalities have greatly improved the results afforded to people suffering from afflictions of the musculoskeletal system.

Some of the new advances which have expanded the science base include:

- Research on osteoarthritis has identified protein factors, such as interleukin 1, that may cause abnormal behavior of cartilage cells and the enzymes that damage cartilage cells.
- Increased understanding of bone growth, metabolism and turnover such as growth factors that promote bone remodeling; and new methods for filling in bone defects.
- Significant improvements in the design and materials parameters of prosthetic joint replacement devices.
- Cloning of collagen genes in progress; with identification of specific genetic defects.
- Although collagen is the most prominent component of the extracellular matrix of bone, other proteins have recently been identified. Osteopontin, a noncollagenous protein has a role in the formation of bone in the growth plate, and possibly, in the normal process of bone remodeling.
- Recognition of specific DNA content patterns in cells of malignant bone and cartilage tumors which allow accurate prediction of tumor behavior (and thus selection of appropriate treatment methods for each individual case).

## Research Opportunities

The research opportunities in this Institute reflect the intellectual richness and vitality of the scientific community committed to addressing the myriad of arthritis, musculoskeletal, and skin diseases. The following are but a few of the exciting opportunities warranting support:

- Research on the causes of osteoarthritis, its pathophysiology, early diagnosis via serum markers, preventing its progression and better methods of improving function in the diseased joint with the ultimate aim of promoting biological repair.
- Research directed toward isolating and formulating biosynthetic bone grafts to supplement and enhance bone repair. The prime bone inductive principles are currently being isolated and synthesized by recombinant methods and are under intensive clinical evaluation.
- Basic research to develop better design, materials, and fixation techniques for joint replacements and other skeletal implants.
- Research on treatment of joint injuries that may lead to premature arthritis.
- Research on the pathophysiology of back pain in order to provide a rational approach to decrease the impact of this major disorder on society.
- Research on bone diseases such as osteoporosis, which weakens the skeleton.
- Research to determine the effects on genetic predisposition, diet, hormones, and environment on the severity and incidence of these diseases.
- Studies to identify optimal levels of physical fitness and equipment modifications necessary to reduce the number of injuries caused by sports, so important to our quality of life.
- Studies to identify methods of reducing the incidence of metabolic diseases through prevention.
- Studies to delineate the factors that are important in improving the acceptability and utility of bone, cartilage and ligaments used for transplantation.

## Intramural research--a source of new research opportunities

The intramural research program of NIAMS has a distinguished record of scientific achievement and represents a unique resource to the biomedical community of the Nation. The orthopaedic laboratory has developed a research program conducting basic investigation at the cellular and molecular levels into the pathophysiology of diseases of the musculoskeletal system. The laboratory provides training for young orthopaedic surgeons and residents interested in basic research. The goal is to teach investigators research techniques and skills that they can use in basic studies of bone, cartilage, etc. Unfortunately, recent and current budget constraints have required NIAMS to reduce the size of its program. This occurs at a time when it is vitally important that the intramural program be in a position to take advantage of the multitude of opportunities for application of creative, state-of-the-art approaches to the complex research problems being addressed in the Institute. We urge the Committee to provide an additional $7 million to expand this important element.

Mr. Chairman, treatment of musculoskeletal diseases has dramatically changed over the past two decades, as a result of improved knowledge of the basic nature, causes and natural history of the disease processes. New technology involving diagnostic and treatment modalities has greatly improved the results in people suffering from afflictions of the musculoskeletal system. The new technologies have permitted individuals to become ambulatory and independent. In short, the new knowledge has improved the quality of their life and reduced their dependence on society as a whole.

Unfortunately, the President's budget for 1991 does not meet the needs of biomedical research. The efforts of this committee to maintain the momentum in science and its attempts to bring hope to those individuals suffering from disease are cut short in the 1991 budget.

In fact, Mr. Chairman, since its inception as a separate Institute, the NIAMS has only been able to support a very low percentage of its approved research grants--a level far below the NIH average.

With this in mind, we respectfully urge this committee to provide $226 million for the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

On behalf of the over 15,000 members of the American Academy of Orthopaedic Surgeons, I want to thank you for your past support and for giving me this opportunity to testify today.

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## STATEMENT OF THE NATIONAL CONGENITAL PORT-WINE STAIN FOUNDATION

On behalf of the National Congenital Port-Wine Stain Foundation (NCP-WSF) I would like to thank the committee for including this written record as part of its' testimony.

The port-wine stain, or nevus flammeus, is a congenital malformation of the capillaries and venous structures that occurs as early as six weeks into prenatal developement. Most of these appear on the face, but can occur anywhere on the body, classically being pink to purple in color, with no definite boundries.

Each year an estimated five in one thousand children born are afflicted with the port-wine stain; of those five percent have associated glaucoma, mental retardation, and uncontrolled seizures due to involvement of the central nervous system which is called Sturge-Weber Syndrome. Port-wine stains tend to darken with age becoming raised thus adding deformity to the skin surface, which can lead to profuse bleeding following even minor trauma.

The approximate seven million Americans afflicted with the port-wine stain will testify to the fact that this is not just a birthmark. This is not just a cosmetic problem. This is truly an affliction that soars psychologically, developementally, socially and vocationally. Personality development can be adversely influenced due to the emotional trauma caused by those ignorant to the real cause of the stain. Financial burdens can be endless with the need for continuous and frequent medical followups by specialists including dermatologists, opthalmologists, and neurologists. Employment opportunities can be affected; though not legal; in this real world we all know appearance counts.

Two years ago my family became one of those affected by the port-wine stain. My son, Michael Scott, was born with a port-wine stain covering the right side of his face from the tip of his lip to the hairline. The shock of my son's physical appearance was devastating but then came the diagnosis of Sturge-Weber Syndrome. Numerous tests were preformed including; cat scans, glaucoma testing, retinal exams, and neurological exams. Due to the lack of sufficient research the outcome of my son's physical and mental development was, and still is unknown. Unfortunately only research can tell what the prognosis will be for my son, and the millions of Americans like him afflicted with port-wine stain and Sturge-Weber Syndrome.

The National Congenital Port-Wine Stain Foundation requests funding for the National Institute of Arthritis, Musculoskeletal, and Skin Diseases (NIAMS). NIAMS has increased opportunities for skin disease research, and must be funded to meet with the needs of this ever increasing patient population. Funding is not only needed to seek new and successful treatment, but also to educate the professional and patient population, and encourage support for basic science research. We urge this committee to increase the NIAMS budget by fifty million, leveling it with the other NIH Institutes in terms of the percentage of approved grants, from 16.6% to 28%. This support is urgently needed for; clinical trials, four additional skin research centers, training of sixty additional researchers, and increasing the intramural research program by seven million dollars. The NIAMS has the lowest funding rate of the entire NIH, further discouraging much needed individuals from considering a career in research.

We must look to the future to protect scientific advances, and bring closer the day when valuable research will end unnecessary suffering.

We thank the Congress for its support of biomedical research funding. We thank you for consideration of our request and we hope you will continue to make investments in science.

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## STATEMENT OF THE ECZEMA ASSOCIATION FOR SCIENCE AND EDUCATION

As a member of the Eczema Association for Science and Education, a patient support group formed in Portland, Oregon two years ago, I wish to add my testimony to that submitted to the Committee.

I urgently support increased funding for the National Institute of Arthritis, Musculoskeletal and Skin Diseases of the National Institute of Health.

Last month, as part of a group of skin disease organizations (The Coalition of Patient Advocates for Skin Disease Research), I had the honor of meeting with a few of the scientists and doctors who work at NIH. They told us of new treatments being developed for skin diseases that will hopefully eliminate our previous dependency on cortisone drugs; we learned of advances in genetic sciences that give us hope for our children's lives that we never dreamed possible. We also were told of valuable research projects going unfunded - projects that were deemed worthy by the Nation's medical and scientific experts. We were warned of the decreasing numbers of young men and women pursuing research careers because of the uncertainty of funding.

I have the disease known as atopic dermatitis (eczema). I have had it for 36 of my 47 years and I have good reason to believe it will be with me for the rest of my life. Eczema is a jailer; my prison is my skin. My waking life is determined by what my skin is allowing me to do that day - do I get to garden today, play with my children, go for a walk? Or do I need to stay in a carefully controlled environment swathed in thick ointments and fearful of any passing breeze that might set off a frenzy of uncontrollable itching? I must always view change with alarm; what will my skin think of this new direction - will it lash back at me or allow it to proceed?

For me the future holds the possibility of severe and crippling osteoporosis because of the vast amounts of cortisone drugs I have taken to just hold my disease at bay (but never cure it). I must always guard against infections, for my skin is frequently covered with open wounds. I must wonder if my children or their children will face the painful life I have lived because no one seemed to care that the research that might have helped them was left undone for lack of funds.

I am fully aware of how much this Committee has done for us in the past; I would have no wonderful discoveries to dream about were this not the case. I thank you for the support you have given in these times of dwindling funds and ever-increasing needs. As a patient who must live with pain on a daily basis, however, I must also ask that you give more - for my sake and the others who dread their daily lives in the prisons of their skins.

On behalf of the Eczema Association and the Coalition of Patient Advocates for Skin Disease, I thank you for your support.

# STATEMENT OF THE NATIONAL PSORIASIS FOUNDATION

Mr. Chairman and Members of the Subcommittee:

On behalf of the National Psoriasis Foundation, I appreciate the opportunity to submit a statement to the Committee regarding funding of the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS) of the National Institutes of Health. Since many people that have psoriasis have benefited from the work of NIAMS and its predecessor, the National Psoriasis Foundation is concerned over the level of funding of NIAMS so that it can continue to help Americans afflicted with the diseases that come under the purview of this Institute. Specifically, we are asking that Congress provide $50 Million above the President's FY 1991 budget allocation for NIAMS.

As someone who has had psoriasis for the last 20 years (I am 37) and whose father and two brothers (my only siblings) have had this incurable skin disorder, I am intimately aware of the impact of psoriasis. Additionally, I have been involved with the National Psoriasis Foundation for almost six years and I have been deeply affected by the many first-hand accounts of other peoples experiences of the effects of psoriasis. What words can one say to the 11 year old girl who has been sent out of her classroom several times because her teacher believes the "spots" on the student's skin are an infectious condition, despite attempts to educate the teacher that psoriasis is not contagious?

At least 4 Million Americans have psoriasis, which means that 2 people out of every 100 is afflicted. Some people are so severely affected that they cannot work and they require hospitalization. There are extreme cases where total body coverage of psoriasis obstructs the regulation of body temperature, causing internal organ failure and even death. Though most psoriatics do not have to deal with that kind of physical impact, all of them are psychologically affected to some degree and many alter their lifestyle from those who have normal skin. For myself, I think I am fairly well-adjusted and open about having psoriasis, yet I will not go swimming or sunbathing at any public location. And though I have never had such thoughts, I have talked with more than one person who has contemplated suicide because of the impact of this disorder.

Yet, with the efforts of NIH and the support of Congress, there has been dramatic improvement in the treatment of psoriasis in the last 20 years. One treatment known as PUVA resulted from research at NIH; PUVA is now widely used and it has been instrumental in enabling many patients to lead more normal lives. Also, the NIH assisted in developing a retinoid drug called Tegison (approved in 1986), which is used mainly to treat those people afflicted with pustular psoriasis, a severe and less common form of psoriasis. One man helped by Tegison had developed severe pustular psoriasis at age 16, causing him to be bedridden and out of school. The drug markedly improved his condition and allowed him to resume school; now 10 years later, he has finished college and started his career, though he continues taking the drug. Without this medication, this man might have been dependent upon public assistance. Tegison has enabled the man to contribute to our economy.

NIAMS research in progress is producing insight into skin mechanisms that have application in a number of skin diseases. And scientists are learning how to grow skin tissue, which could be beneficial to both skin disease and burn patients. Moreover, this Institute also deals with arthritis and musculoskeletal diseases, which are the leading cause of disability in the United States. A large number of Americans are affected by diseases that are of concern to NIAMS - for example, 37 Million people of all ages are afflicted with arthritis, 27 Million have osteoporosis and related bone disorders and 60 Million people are treated annually for skin diseases. The economic cost (including work loss) of arthritis, musculoskeletal and skin disease is substantially over **$100 Billion per year.** Thus, it is vital that we continue the progress at NIAMS through increased funding. Unfortunately, NIAMS has been negatively impacted by this era of tight budgets because the Institute was created in 1986. While Congress has been sympathetic and supportive, NIAMS still lags behind the other Institutes within NIH. Having the lowest funding rate of all the Institutes, over 83% of approved NIAMS research grants go unfunded. Many excellent proposals have died due to the lack of money. And in terms of constant dollars, the NIAMS budget has grown only 2% since the Institute was established.

These figures are very distressing to me and the National Psoriasis Foundation because of the repercussions within the biomedical research community. Many young researchers are opting for careers in other fields or in private medical practice due to the lack of resources at NIAMS. The NPF has experienced this directly; we have awarded post-graduate fellowships to several young scientists that have left the field because they cannot get greater funding and/or they see their mentors having grant proposals go unfunded. Also, our medical-scientific advisors tell us that they see very few young people following in their footsteps.

The declining percentage of grants funded by NIAMS and NIH threatens the position of the United States as the world leader in scientific research and our ability to help more of our citizens to lead productive, fulfilling lives. While I realize that we have a deficit to deal with and that there are many worthy needs competing for budget resources, I feel that we must look at increased funding for biomedical research as an important investment in our future that will reap definite benefits for our society.

Increasing the NIAMS budget by $50 Million above the President's allocation would allow the percentage of approved grants to increase to 28% from the current 16.6%, thus giving NIAMS parity with the other institutes in NIH. It would also enable the institute to train 60 additional researchers, fund 4 more research centers and it would add $7 Million to the intramural research program. Further, it would support clinical trials that are so crucially needed.

It is for the reasons I have detailed above that I strongly urge this Committee to provide additional funding for NIAMS. Please continue to invest in science and our citizens. Your past support of biomedical research has helped many Americans in many ways and I am sure that you have their gratitude. I share in their gratitude and I thank you for the opportunity to express my views to the Committee.

# STATEMENT OF THE NATIONAL VITILIGO FOUNDATION, INC.

Mr. Chairman and members of the Committee, I am Allen C. Locklin. I have been honored in the past to appear before this committee along with members of several other skin groups and wish to thank you for that and the opportunity to again offer testimong for your consideration. I am a geologist and President of a small oil company. My wife and I are co-founders of the National Vitiligo Foundation, Inc., a non profit, charitable foundation formed to find, inform and counsel all Vitiligo patients and their families; to increase public awareness and concern for a patient within the medical community and to encourage, promote and fund increased scientific and clinical research on the cause, treatment and ultimate cure of Vitiligo.

Vitiligo, a non-contagious but hereditary disease is, as you can see from the enclosed color photographs, a disfiguring disorder resulting in pigment loss in the skin, showing as white patches. Except for itching and dryness of the skin and a greater chance for sunburn, there is no physical pain. But, as anyone who is the least bit vain can see, it presents a most disfiguring appearance, leading to extreme phychological and emotional problems for the patients, including suicide. Marriages, jobs and social activities are extremely effected by the occurrence of Vitiligo. Two years ago a young soldier was discharged from the army because of his Vitiligo, as being a socially unaccepted problem. Children in particular are subject to taunts, isolation and being ostracized because of their Vitiligo. Approximately 50% of all the patients have their Vitiligo before age 20.

The Vitiligo patient faces a greater risk of having Hyperthyroidism and Hypothyroidism, Pernicious Anemia, Addison's Disease, Alopecia Areata and Uveitis. It also appears that some connection exists between Vitiligo and melanoma, the deadly form of skin cancer.

Many patients literally withdraw from society, others disquise their problem by wearing long sleeves, high collars, makeup and stains. Basically, each patient wants to be just one color. Vitiligo is not life threatening but is is: "Life Altering".

Vitiligo effects all races equally. It is, however, more apparent in darker skin tones due to the sharp contrast between the white blotches and the pigmented areas. It is estimated that beetween 1% and 2% of the world's population has Vitiligo, which translates into 2½ and 4½ million Americans having the disease.

As a Vitiligo patient who has suffered the devastating effects of the disease, I have been trying to make a difference in Vitiligo. Our foundation is only 4½ years old, and it is very apparent that the

Vitiligo patient has long suffered in silence and they are overjoyed to know someone is trying to help them. I have received letters and phone calls from around the world. We now have enrolled over 1250 doctors in 50 countries concerned about Vitiligo and anxious to help. These doctors are basically up to date on Vitiligo and its treatment and are eager to learn of new research. We are acting to some degree as a clearing house for them. Currently, we are examining information from other countries, including China, Egypt and Cuba. The Cuban drug Malaginina has received attention from around the world with patients eagerly traveling there at great expense to seek a cure. The drug is currently under scrutiny in the USA but is not yet approved for use here.

Two members of our Medical Advisory Board attended a Melagenina Vitiligo Conference in Havana, Cuba in June of 1989 and based on their findings and given the current availability of research data the drug does not offer much encouragement for an effective treatment for Vitiligo for most patients.

Of considerable interest is an herbal treatment offered by Dr. Jin Qixiang on Visa from China in Bangkok Thialand. Many patients have trekked to Bangkok to receive the treatment which does show promise. The Egyptian drug Khellin was expected to have been approved within the last 12 months. Doctor Rebat Halder has done extensive research on this drug, but final approval is still forthcoming.

Unfortunatley, many patients with Vitiligo have been told by their doctors to, "Just learn to live with it". This is clearly wrong. There is hope. There are forms of treatment that offer some success for repigmenting. It is time consuming, tedious and expensive, but to some, it is worth it.

For the most part, treatment has only slightly improved over thousands of years. We still rely mainly on the psoralen drugs which were first used by the Egyptians 4000 years ago. You can see that we have not come very far. Research is going on, thanks to this committee, but, it is very limited and much more is needed. Certainly any cuts in funding would be very detrimental to the program.

Vitiligo falls under the National Institute of Arthritis and Musculoskeletal and Skin Diseases designated by Congress in 1987. With the exception of some very small individual grants, only the money budgeted to the Consortium of Yale, Massachusetts, Cincinnati and Howard Universities is directed toward Vitiligo research. We support the level of funding proposed for FY 1991 by the Coalition of Voluntary and Professional Associations Concerned with Programs of the NIAMS from which that money is derived.

We were most gratified by the support Congress gave in 1990. It is most important to point out that the cross-over benefits of research can often lead to discoveries that aid patients with diseases other than that being researched. This adds importance to the need for continued funding for research on the many disease problems of the populace.

Once again, I would like to thank this committee for its concern, compassion and support of the many skin disorders you've so patiently evaluated by listening to, reading about and observing the patients and their needs.

Thank you.

# NATIONAL HEART, LUNG, AND BLOOD INSTITUTE

## STATEMENT OF THE TREATMENT OF HIGH BLOOD PRESSURE FOR PUBLIC ACTION ON CHOLESTEROL, INC.

Mr. Chairman and distinguished Members of this Subcommittee. It is a privilege to have this opportunity to testify before you regarding federal programs which target funding toward the prevention of cardiovascular heart disease. My name is Jerry Wilson and I serve as the Executive Director of Citizens. In testifying before this Committee over the years, many of our distinguished leaders have appeared including Dr. Michael DeBakey and Mrs. Mary Lasker, co-chairman of our Board of Directors.

**Role of Citizens**

Citizens role is to advocate in the area of public policy and resources for heart disease prevention. Citizens for the Treatment of High Blood Pressure was established in 1973 as the private sector counterpart to the federal government's National High Blood Pressure Education Program. Citizens for Public Action on Cholesterol was created in 1985 to augment the federal National Cholesterol Education Program and expand the private sector's involvement in cholesterol education and advocacy.

**Cardiovascular Heart Disease is Nation's Leading Cause of Mortality**

Cardiovascular disease remains the number one killer in the United States. One in three adults has high blood pressure and, of those with high blood pressure, 75% are not controlling it. In the area of cholesterol more that 50% of adults have cholesterol in excess of the recommended 200 mg/dl, and, of these, one in three has levels that require a physicians' care. Clearly, much more can be done to educate the public to prevent this disease. Yet in most states heart disease prevention is the lowest priority as measured by state spending.

**Federal Funding of Heart Disease**

Today, Citizens is advocating for 1) increased funding within the National Heart, Lung, and Blood Institute (NHLBI) , with special emphasis on the public education programs and 2) increased funding for Chronic Disease and Environmental Health within the Centers for Disease Control (CDC).

**NHLBI /The President's Budget Request**

The FY 1991 President's budget request for the National Heart, Lung, and Blood Institute is $1,112,502,000. These funds will allow the Institute to continue basic, clinical, and population-based studies designed to identify risk factors for cardiovascular disease. In particular, Citizens is supportive of the attention NHLBI has shown toward eleven southeastern states where the death rates from stroke are so high as to warrant the designation "stroke belt." Among Blacks in those States hypertension is more prevalent, more severe, and less controlled, and obesity is more common than among Blacks in other regions. The National High Blood Pressure Education Program has developed a multifaceted stroke belt intervention strategy to address these problems.

**NHLBI/Citizens' Recommendation**

The President's Budget proposes a 3.7% increase over FY 1990 for NHLBI. Citizens believes this is inadequate to meet the research and public education needs and recommends funding at a level of $1,482,473,000. At this level, the Institute would restore negotiated reductions, continue educational programs as described above, and pursue several new initiatives in basic and clinical research and in the area of public education. Citizens is particularly supportive of a new educational program that has a goal of effectively reducing the time between onset of heart attack and admission to an intensive care setting. This program will target physicians and help them educate their patients about signs and symptoms of heart attack and help patients develop appropriate contingency plans should prolonged chest pain occur. It is called the National Heart Attack Early Action Program, and builds upon data indicating the first few hours after the onset of a heart attack to be the most dangerous. This program will join NHLBI's current high blood pressure, smoking, cholesterol, asthma and blood supply education programs. Citizens believes that these additional funds should ensure the quality of ongoing as well as new educational initiatives.

**Center for Disease Control/President's Budget Request**

Within the Centers for Disease Control, Citizens is particularly concerned with two programs--the preventive health services block grant and the chronic and environmental disease prevention budget line item.

**Preventive Health Services Block Grant** funds for 1991 are recommended to continue at funding levels approved for 1990. The block grant funds are a key mechanism for supporting preventive health services in the states through direct program operations by Federal staff, cooperative agreements, and categorical programs.

**The Chronic and Environmental Disease Prevention** funding has been recommended to increase from $51,323,000. to $78, 973,000. Chronic disease prevention is based on early detection of disease and on controlling risk factors which can prevent occurrence and progression of disease. Citizens is supportive of activities funded through this program such as the South Carolina Cardiovascular Disease Prevention Program. The program, based in Florence, South Carolina, is designed to make it easier for people to take care of their hearts by encouraging citizens to participate in heart healthy programs set up by their churches, schools, neighborhoods, and places of work. The program includes an evaluation to measure the process of implementing the program (such as, number of brochures distributed, number of citizens screened), and the effectiveness of the program( percentage of citizens reducing intake of salt, lowering blood pressure measurements,and lowering cholesterol measurements, to name a few). This is done by contrasting changes in Florence over time with those observed in a comparison community in the state. The overall objective of this community-based program is to apply current research findings at the state and community level.

**Centers for Disease Control/Citizens' Recommendations**

Regarding the **Preventive Health Services Block Grant**, last year we brought to the attention of your committee our concerns about the collection of reporting data. This Committee directed CDC to provide specific funds to expand a pilot program to all states which demonstrate improved reporting. We are pleased to report that CDC has collected most of this data. In the area of cardiovascular disease, for example, the preliminary data describe expenditures for hypertension services as well as activities related to hypertension services (including number of persons screened, number referred for physician follow-up, number brought to pharmacologic treatment and number contacted and determined to be in compliance, to name a few.) From this data we have a better idea as to the extent of cardiovascular services being provided in the States. Today the purchasing power of this program is probably only 50% of when it first started in 1982. An informal survey of hypertension program managers in the States reveals an alarming lack of funds to carry out outreach services at the city and county level. Therefore, with the reporting data in place we believe the timing is right to increase funding from $85,210,000 to $ 110,000,000. However, we urge the Committee to further direct CDC to target delivery of services to minorities and populations at risk of disease and to document this in evaluation data. In addition, we believe state programs may need to strengthen the components of their programs which follow-up the screening services--physician referral and treatment.

Regarding the **Chronic and Environmental Disease Prevention** item, according to a CDC report ( Washington Post, February 20, 1990, p. 5.) less than two percent of state public health expenditures are allocated to prevent and control chronic disease. The average state expenditure is 66 cents per person per year. This situation must be improved. Therefore Citizens recommends increasing funding to a level of $ 92,500,000. This will allow for expansion of efforts underway to vigorously translate chronic disease research findings into practical public health programs.

**Summary**

Every 32 seconds someone dies of cardiovascular disease. Citizens believes that prevention programs, including public education, are an essential component to stopping this number one killer. Thank you for the opportunity to testify before you today. I would be pleased to answer any questions that you may have for me.

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## STATEMENT OF THE AMERICAN COLLEGE OF CHEST PHYSICIANS

Mr. Chairman and Members of the Committee:

I am Dr. Edward C. Rosenow, III, President of the American College of Chest Physicians. I am also the Arthur M. and Gladys D. Gray Professor of Medicine and the Chairman of Thoracic Diseases at the Mayo Clinic in Rochester, Minnesota.

I would like to begin by thanking you for affording me the opportunity to submit this testimony for the record on behalf of the American College of Chest Physicians. ACCP is a professional medical specialty society of more than 13,000 physicians, scientists and educators who specialize in diseases of the heart, lungs and circulatory system. The College appreciates this opportunity to offer its views to this Committee on Fiscal Year 1991 appropriations for the National Heart, Lung and Blood Institute (NHLBI).

I would like to preface this statement by emphasizing that ACCP enthusiastically supports the activities of the National Institutes of Health, particularly those of NHLBI. We unequivocally support NIH's commitment to support the entire spectrum of research, both basic and applied, as well as for treatment and prevention. We also are impressed with the quality of leadership of NHLBI by Dr. Claude Lenfant.

With respect to funding levels, ACCP believes that in order for NHLBI to be able to fulfill its mandate and provide the leadership which is crucial to our national biomedical research effort, an NHLBI non-AIDS appropriation of $1.412 billion is necessary for Fiscal Year 1991. I am concerned that the total NIH budget of only $6.7 billion is roughly equivalent to the cost of one Trident submarine, or 60 B2 stealth bombers or 100 M1 tanks. This $6.7 billion represents only 1% of the $600 billion spent in health care dollars. This 1% is too low; if more appropriately applied, this money would ultimately help in reducing the total health care dollars spent.

Another major concern I have is the declining interest in the sciences by the young people in our country. It is a well known fact that high school students are not attracted to the sciences in college, and in turn less qualified ones go into medicine. Those in medicine, because of the tremendous debts accrued, cannot "afford" to go into research; but if they are still interested in research, fewer are successful because of the relative decline in research dollars. With a decline in critical mass in research, I estimate it may take us 10 to 20 years to catch up, even with sufficient allocations of funds. We will fall behind as the leaders in research in the world.

In total the College wishes to express its support for an appropriation level of $9.237 billion for Fiscal Year 1991 for the National Institutes of Health (NIH). This recommended level of funding would be consistent with our national commitment to biomedical research and would translate into an appropriate, sound, and progressive level of NIH research activity which accurately reflects its vital mandate.

Turning to the excellent work of NHLBI, under the very able leadership of Dr. Claude Lenfant, tremendous strides continue to be made in combatting cardiovascular and pulmonary diseases. ACCP's recommendations are aimed at maintaining that momentum. Although we recognize the strains that have been placed on the federal budget in recent years, the fact that diseases of the heart and lungs continue to pose the most serious threat to our Nation's health must not escape us. The desirability of exercising fiscal austerity should not cause us to lose sight of this fact.

According to NIH statistics, cardiovascular diseases afflict more than 70 million people. In 1986, 979,000 deaths or roughly fifty percent of all deaths were attributed to cardiovascular diseases. In addition to the untold costs of human suffering, cardiovascular diseases are responsible for a loss of well over one hundred billion dollars each year in productivity, wages and costs of medical care. The most telling statistic, however, is that cardiovascular diseases continue to be the number one cause of death in this country. Diseases affecting the lungs are the fifth leading causes of morbidity and mortality. Indeed, if one adds lung and blood diseases to the tally, the stark reality is that 1,159,000 deaths in 1986 or over fifty-five percent of all deaths fall within the disease categories that is the mission of NHLBI to combat. These diseases represent five of the ten leading causes of death. And yet despite this fact, NHLBI's allocation among the NIH institutes amounts only to approximately fifteen percent. As the Surgeon General has pointed out, smoking alone accounts for 400,000 premature deaths per year at a cost of $52 billion. We must have help in ridding society of this scourge. Towards this end, the College strongly supports Secretary of Health and Human Services Louis W. Sullivan's efforts to create a smoke-free environment by the turn of the Century.

Two points need particular emphasis. First, while the effort of NHLBI have helped lead to a significant decline in the death rate from pulmonary and cardiovascular diseases over the past twenty years, the incidence of these diseases and their costs, in terms of human suffering, death, and economic loss remains staggering. Second, when one views the progress made to date and takes into account the costs that would have been incurred had it not been for the work of NHLBI, the conclusion is clear: monies spent to combat these diseases have been monies well spent. Indeed, I believe it fair to say that for every dollar spent by NHLBI, the return in terms of dollars not spent on health care, etc. exceeds most other expenditures by the Federal Government.

It is therefore imperative that NHLBI be afforded sufficient resources to continue its efforts to combat the full array of pulmonary and cardiovascular diseases.

NHLBI's commitment to the study of diseases of the heart and lung is evidenced most clearly in its integrally-linked chain of research methodologies. Comprised of basic research, clinical investigation and development of preventive medicine programs, this system demonstrates the tangible advances which have been made available to the American public through the sponsorship of NHLBI. We remain grateful for the support we have received.

Today, ACCP continues to lend its support to those research efforts by virtue of the fact that 40% of our members voluntarily donate every year, extra dollars to the College towards supporting young investigators; we believe this is unique compared to other medical societies. We are committed to improving the quality of the lives of the most important people we represent -- our patients. But we can not do it alone. NIH appropriation levels must be increased to insure that our progress toward that goal is not thwarted. The Federal Government must not turn its back on biomedical advances of the future which would yield billions of dollars in health care savings. Funding levels consistent with the important goals and essential mandate of NIH must be achieved. On behalf of ACCP's membership, I would like to thank you for affording us this opportunity to present our views.

# NATIONAL INSTITUTE ON AGING

## STATEMENT OF THE OSTEOGENESIS IMPERFECTA FOUNDATION

Senator Harkin, and members of the subcommittee:

Please accept this written testimony on behalf of myself, my family and the entire membership of the Osteogenesis Imperfecta Foundation. The OIF is a national, voluntary health care organization dedicated to supporting and furthering research and education on osteogenesis imperfecta and its related disorders. Osteoporosis, one of the better known of the brittle bone disorders affects more than 25 million individuals in the U.S. Osteoporosis has become the single most important women's health issue of this last decade of the century.

In years past, Mrs. Roberta DeVito and her son Congie have asked this committee to create a broad mandate to NIH. You, in a very real sense, paved the way for my daughter Brianne to live a far more active life than anyone could have dreamed possible just a short ten years ago. Brianne is not a miracle child. She is the product of ten years of NIH research.

1. Manifestation

Ask any parent of a child with OI and they will tell you a similar story. Ours goes like this. Brianne was born on April 9, 1980 with so many broken bones she was given very little chance for survival. We were told to be prepared to institutionalize her should she survive since her life would be one of countless fractures that would require professional care. I will always remember sitting in the dark nursery with my baby listening to her tiny ribs break each time she hiccupped.

Other complications of OI include:
  stunted growth
  deafness
  respiratory incompetence
  heat sensitivity
  corroding teeth
  loose joints
  easy bruising
  bone deformities and scoliosis

In milder forms of OI where diagnosis is not as readily made, parents have been suspected of child abuse when unexplainable fractures and bruises occur. A dear friend of mine whose husband was a Wisconsin State Representative was relentlessly investigated for child abuse until a definitive diagnosis of OI was made.

2. Prevalence

Although the brittle bones diseases as a group affect a very large group of people (over 25 million), research on these disorders carries the lowest proportional grant award rate within all of NIH.

3. Research

My ten years of personal experience with researchers at the NIH clinical center has shown me what tremendous strides have been made in OI research. It is now known through the efforts of a NICHHD researcher that the short stature associated with OI is related to deficiencies either in growth hormone or another hormone called somatomedin-C. Currently, mechanisms of bone remodelling and the problems associated with a defective matrix are receiving attention. The research that has most impacted our lives is the bracing protocol which has allowed Brianne to experience life standing up. Her braces are at times uncomfortable and hot, but with them on she can attend a regular elementary school without all of the peripheral services that would have been necessary had she remained bedridden these past 10 years. This alone is a great return on the NIH research investment dollar. Brianne still faces frequent fractures, fractured teeth, scoliosis and perhaps a shortened life span. She is one of the lucky ones. The majority of infants and children afflicted with osteogenesis imperfecta are not even being treated!

CONCLUSION

We ask that sufficient funds be made available for basic research and training grants so that young investigators will be attracted to and trained for the field. Funding for post doctoral fellows to work in the laboratories would contribute a great deal to the actual data collection and bench work needed to get at the physiological mechanism of this disorder. It is our view that implementation of these mandates will greatly increase the momentum of research in the field of metabolic bone diseases, and thereby, create the movement that would vastly improve the quality of life for the increasing millions of victims of brittle bones. For the hope you have given me as a parent, for the life you have given to my daughter Brianne and the other children who have directly benefited from NIH research, we offer you our gratitude and respect. The pieces of the puzzle are slowly starting to show up on the board, we just have to pick them up and put them together. Thank you.

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## STATEMENT OF THE AMERICAN GERIATRICS SOCIETY

The American Geriatrics Society (AGS), is pleased to have the opportunity to express our organization's views regarding FY 1991 funding for the National Institutes of Health (NIH), particularly the National Institute on Aging (NIA).

The American Geriatrics Society (AGS) is an organization of almost 6,000 physicians, nurses, and other allied professionals dedicated to the advancement of research, education, and clinical practice related to the medical care of older persons. The programs of the National Institutes of Health, and particularly the National Institute on Aging, are extremely important to AGS members, many of whom receive NIH support for their research.

Opportunities in biomedical research have far out-paced funding growth, and many high-quality proposals have gone without support. With regard to NIA, this situation is compounded by the fact that budget increases provided in recent years have been targeted predominantly to studies of Alzheimer's disease, which is a major research focus for many of our Society's members. However, we believe that funds should be added to the NIA budget to support Alzheimer's research rather than simply diverted from other important NIA efforts. A report recently issued by the Pepper Commission recommended a $1 billion Federal spending goal for research to curtail long term care needs. Alzheimer's disease was cited as one of a number of diseases that should be supported with these funds. The Commission also noted the need for research funding increases for studies of osteoporosis, breast cancer, and urinary incontinence.

The Subcommittee has expressed concern about the targeting of overall NIH support to AIDS outside the peer review process. We suggest that this same principle should apply to the NIA and its efforts. The Congress is correct in identifying AIDS and Alzheimer's disease as major health threats. However, increased research activity in these areas must be in addition to, not at the expense of, research focused on other diseases that produce severe disability.

For FY 1991, the AGS supports the proposal of the Ad Hoc Group for Medical Research Funding, which recommends an overall NIH budget of $9.237 billion. Specifically for NIA, we recommend an FY 1991 budget of $313.6 million, which is a 26% increase above the President's request. This amount would fund a total of 698 grants, 92 above the President's request (30% of approved proposals); 245 competing grants, 92 more than the President's request; 473 trainees, an increase of 85 over the President's request; 29 centers, 5 more than the President's request; and 104 career awards, 13 over the President's request.

In particular, the AGS believes the following areas merit special attention:

- Frailty Clinical Trials: The NIA has planned clinical trials of interventions designed to reduce long term care needs and injuries associated with physical frailty. Such interventions include exercises, rehabilitation strategies, nutritional interventions, fall and hip fracture prevention programs, and environmental/behavioral factors. These trials are crucial if we are to improve the independence, quality of life, and health of the frail elderly. For FY 1991, we recommend $5.5 million for frailty clinical trials, which is a $2.6 million increase over the President's request. This level of support will fully fund a total of twelve projects, compared to the eight that received only partial funding in the current year.

- Geriatric Assessment: A recent NIH Consensus Conference panel noted the value of geriatric assessment in improving health outcomes and reducing health costs, and recommended research to further improve assessment strategies. Research on geriatric assessment will refine this strategy for identifying persons with treatable and preventable disabilities and assuring proper treatments and services which may reduce long term care needs. We recommend $3 million, $2.5 million over the President's request, to enable NIA to fund several planned projects on geriatric assessment.
- Frailty in Minorities: Genetic and environmental factors can increase risks for disabling disease and the inability to cope with frailty and its consequences. Studies must address these factors in different groups if we are to develop effective strategies to reduce frailty and disability among minorities. For FY 1991, the Society recommends $2 million, $1.7 million over the President's request, for such studies.
- Claude Pepper Geriatric Research and Training Centers: These "centers of excellence in geriatric medicine" address the shortages of faculty members and other health care professionals with adequate preparation in geriatrics. The centers provide training, basic and clinical research opportunities, and a varied patient care experience. As several medical fields establish subdisciplines in geriatrics, and as nearly every U.S. medical school re-examines its curriculum in geriatrics, there is a pressing need for these centers so that we can guarantee an adequate supply of high quality geriatricians. For FY 1991, we recommend funding five

Claude Pepper Centers, which, at $1.2 million each, would require a total budget of $6 million, none of which was included in the President's request.

Medical science has enabled us to extend the average life expectancy well into the eighties. We must now focus on making these additional years healthy so that older people are able to remain productive and independent. The majority of the nation's taxpayers believe research to improve health care for the elderly should be a national priority. In a nationwide survey conducted last year for the Alliance for Aging Research, three out of four Americans questioned (76%) said the Federal government should consider a commitment similar to our effort to put a man on the moon for a program of research to insure the health and independence of older Americans.

President Bush has stated that "we should try to reduce the need for care by devoting significant research attention to the prevention and cure of debilitating illnesses...that can keep us from caring for ourselves." The American Geriatrics Society believes that the President should have requested NIH funding increases to support this pledge. The opportunities that exist in our field require a well-funded NIA and a commitment to steady expansion of the overall NIH effort.

# STATEMENT OF THE AMERICAN AGING ASSOCIATION

Chairman Harkin and distinguished members of the subcommittee, my name is Denham Harman. I am Executive Director of the American Aging Association (AGE).

I appreciate the opportunity to testify on behalf of the American Aging Association on the need to increase support of the National Institute on Aging for basic biomedical aging research.

Average life expectancy at birth is a rough measure of the healthy, useful life span, i.e., the functional life span. Better nutrition, medical care, public health facilities, and accident prevention helped to increase life expectancy from 47.9 years in 1900 to 69.2 years in the mid-1950's, and then, more slowly, to 74.9 years in 1989. Conventional efforts to further increase average life expectancy are now almost futile. The chance of death at any given age decreases towards a limiting value as average life expectancy increases. We have now almost reached these limits. Today only 2-3 percent of our population die before age 28. For the rest, the chance of death increases progressively with age in accordance with an inner destructive process, called aging, which ensures that few reach 100 years and none live beyond about 115 years, even in the absence of overt disease and under the best of living conditions.

The aging process is now the major risk factor for disease and death after age 28 and limits average life expectancy at birth to less than about 85 years. These facts are obscured by the protean nature of its contributions to non-specific change and to disease pathogenesis, i.e., cancer, atherosclerosis, and Alzheimer's disease. As recognized "risk factors" for diseases are minimized the chance of death decreases towards that determined by the aging process.

The functional life span could be significantly increased by slowing the rate of damage production by the aging process. Many theories have been advanced to account for the process. For example, the effects of aging have been attributed to molecular cross-linking, changes in the body's immunologic functions, damage by free radical reactions and to senescence genes in our DNA.

Unfortunately, the importance of the aging process to our health and well-being is being overlooked, perhaps because of a belief that our past successes in increasing the human life span will continue indefinitely. Funding for basic biomedical research on aging is meager. Only between $25 million and $50 million is available per year, largely from the National Institute on Aging.

The importance to individuals and to society of further increasing the functional life span mandates a major national program to determine the cause of the aging process and the practical means of slowing the rate of damage caused by this basic biological process. As a start, we recommend that $100 million be included for this purpose in the next budget for the National Institute on Aging.

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## STATEMENT OF THE AMERICAN HEART ASSOCIATION

*Cardiovascular diseases and stroke remain the leading cause of death of older Americans. Total cardiovascular disease, including stroke, affects an estimated 84 percent of Americans over age 65. About two-thirds of all medical care expenditures for cardiovascular diseases are spent on Americans over age 65. In 1988, an estimated 27 percent of medicare short stay hospital payments were expended for stays where the principal diagnosis was disease and disorders of the circulatory system.*

*The American Heart Association's (AHA) comments and FY 1991 funding recommendation for the National Institute on Aging (NIA) follow. In accomplishing our mission, the reduction of disability and death from cardiovascular diseases and stroke, the AHA works closely with related Federal research, education, and prevention programs, including the National Heart, Lung, and Blood Institute (NHLBI) and the National Institute of Neurological Disorders and Stroke (NINDS). Also, we have committed our support to the NIA's basic research on aging. The AHA plans to sponsor more research on aging of the heart and blood bessels and on the brain and kidney.*

*From 1963 to 1986, the age-adjusted death rates from heart attack and stroke declined by 49.1 percent and 60 percent, respectively. In part, this dramatic decline is due to the discovery of the cause and effective prevention of rheumatic heart disease, which accounts for close to half of all coronary heart disease and most strokes in younger individuals. Research has also found effective treatment for many serious heart diseases that cause death and disability in younger people.*

*Despite remarkable progress there will be more disability in the United States because many people who have had effective treatment for coronary artery disease and prevention of atherosclerosis at age 40 to 60 will develop heart disease later. Diseases of aging are emerging as a major public health problem. Age is a nonmodifiable risk factor for cardiovascular disease.*

*Cardiovascular diseases and stroke remain the number one killer of older Americans. Heart attack and stroke, the first and third leading causes of death in the United States, respectively, affect* *about 4 million Americans over age 65. Deaths from cardiovascular diseases and stroke rise significantly with increasing age, as does its incidence and prevalence.*

*Nearly 55 percent of all heart attack victims are age 65 and older; of those who die, about four out of five are over 65. At older ages, women heart attacks victims are twice as likely as men to die within a few weeks.*

*High blood pressure, a leading risk factor for cardiovascular disease and the most significant risk factor for stroke, afflicts about 61 million Americans. More than 50 percent of these victims are over 55. Blood pressure tends to increase with age. Men have a greater risk of high blood pressure (hypertension) than women until age 55, when the risk is about equal. Women age 65 and older are more likely to develop high blood pressure than men. High blood pressure is a significant problem among older women. More than half of all women over age 65 have hypertension.*

*For Americans over 55 years of age, the incidence of stroke more than doubles in each successive decade. About 72 percent of stroke victims are age 65 or older. The danger of stroke in people aged 65 to 74 is about one percent a year. If they have had a transient ischemic attack, (TIA), a temporary stroke-like event that lasts for only a short time, caused by a temporarily blocked blood vessel; the chance increases from five to eight percent a year. Stroke is the source of the majority of adult disability, accounting for a significant number of nursing home admissions. Stroke accounts for about half of all patients hospitalized for acute neurological disease.*

*Aging is the most potent risk factor for coronary heart disease and stroke. In an aging population and with longer survival of those with heart disease, there will be more disability. Also, there are forms of heart disease that appear predominantly in the elderly. Aortic valvular obstruction and conduction system changes are frequent in those over age 80.*

*Unfortunately, little is known about age changes in the heart and blood vessels, but what is know is optimistic. Most cardiac disability is due to disease not aging. The idea that most everything deteriorates with age is wrong. Even degenerative heart diseases, such as aortic valve obstruction may be just a disease of unknown cause waiting for more research.*

*Scientific information is limited in one significant group--the elderly. This Nation must make progress in the prevention of heart disease in the elderly. There is a conspicuous absence of significant basic research on the cause of cardiovascular diseases in the elderly. Atherosclerosis, the major cause of heart attack, stroke, and peripheral vascular disease, has been little studied in the elderly. Atherosclerosis clearly progresses in the elderly, but it remains totally unclear what causes progression.*

*Recently, two widely publicized documents emphasized this lack of data and the absence of information on what produces atherosclerosis in the elderly. The congressional U.S. Office of Technology Assessment (OTA), in April 1989, questioned the value of cholesterol screening in the aged. The OTA states in Costs and Effectiveness of Cholesterol Screening in the Elderly, "... the health benefits, particularly as measured by total mortality, of cholesterol screening in the elderly are unproven and may be smaller than in middle-aged people." Stating ,*

> *"... there have been no randomized controlled trials of the health effects of cholesterol reduction in the elderly; ... cholesterol is not as powerful a risk factor for coronary heart disease in the elderly; ... epidemiologic studies have found that the cholesterol level is either not associated with overall mortality rates or is inversely associated with all-cause mortality." OTA concludes that "it would be difficult to infer from available evidence that elderly individuals with an elevated blood cholesterol level would benefit from cholesterol reduction...."*

*While Medicare does not currently pay for cholesterol screenings, OTA speculated that based on complete compliance by the elderly with the National Cholesterol Education Program, in 1995 the cost for their screening and follow-up treatment would be between $1 billion and $5.4 billion.*

*Similarly, in the September issue of "The Atlantic Monthly," journalist Thomas J. Moore cited numerous clinical trials consisting exclusively of middle-aged men. In an excerpt from Heart Failure, Moore notes that,*

> *"... these figures (total mortality from coronary heart disease) apply only to a minority of those at risk: young and middle-aged men. As noted earlier, the relationship between high cholesterol levels and heart attack is weak or nonexistent among the elderly, in whom most deaths from heart disease occur, and among pre-menopausal women, in whom the disease is rare."*

*Because of this absence of information and inconclusiveness of data, the AHA believes that the NIA must make the identification of cardiovascular risk factors and molecular and vascular mechanisms that contribute to atherosclerosis in the elderly a priority research commitment. The NIA, charged with the coordination of government wide research on aging, acts as the chief source of information exchange for aging-related research through the ad hoc Interagency Committee on Research on Aging.*

*Currently, the NHLBI, the NIA, and the NINDS are sponsoring or plan to support several age-related studies in the cardiovascular area. Some examples follow. Co-sponsored by the NHLBI and the NIA, the Systolic Hypertension in the Elderly Program (SHEP), a multi-center clinical trial, is assessing the effectiveness of antihypertensive treatment in reducing the occurrence of stroke and other cardiovascular diseases in the elderly. The NHLBI's Cardiovascular Health Study, concentrating on those 65 to 90 years of age, is studying combination of risk factors in an attempt to distinguish patterns that may predict cardiovascular disease. A NINDS major multi-center clinical trial which evaluated whether aspirin or a low dose of the anticoagulant warfarin would prevent strokes in those with artrial fibrillation, a common type of irregular heart beat in older persons, showed that these drugs reduced stroke incidence by 81 percent.*

*The NHLBI circulated a request for research grant applications (RFA) to plan and execute a pilot study for a multi-center randmoized clinical trial to determine whether HMG CoA Reductase Inhibitors, a new class of potent cholesterol-lowering drugs, will reduce death from atherosclerotic cardiovascular disease in men and women over 60 years of age; awards will be made July 1990.*

*The AHA encourages more joint ventures between the NHLBI and the NIA. More research on basic biological age-related changes is needed. The NHLBI and the NIA have jointly solicited investigator-initiated projects for clinical or laboratory studies to clarify the relationship between disease processes of atherosclerosis and aging through the program announcement Atherogenesis and Aging. Research will focus on the relationship between age-related biological changes and their contribution to the beginning, advancement or regression of atherosclerosis. Scientists will seek to determine whether the reaction to atherosclerosis risk factors, including hypertension and hyperglycemia or treatment is affected by age. They hope to identify age-related changes in metabolism or structure processes which might influence the development or regression of atherosclerosis.*

*Also, the NIA is inviting applications for research on relationships between aging processes and cardiovascular function and disease through the program announcement Aging and the Cardiovascular System. Research in this area is particularly important because age-related changes in cardiac function, circulation, blood pressure, and metabolism of fats (lipids) contribute significantly to disease and death in the elderly. Moreover, age-related changes in the cardiac muscle and valves, the heart's conductive system, the arteries, the small blood vessels, and circulation may have significant effects on cardiovascular function and may ultimately impact the function of other organ systems, including the lungs and the kidneys. Increased understanding of the causes, rates of advancement and relation among these factors may produce preventive and therapeutic measures to reduce cardiovascular diseases in the elderly.*

*The NIA's Laboratory of Cardiovascular Science is conducting age-related research focused on studies of the movement of blood through the human heart over long periods of time. An opportunity exists for the NIA to develop a complementary Laboratory of Vascular Studies. Cardiovascular diseases are often blood vessel-related (vascular). Previous research of vascular function and pathophysiology have, essentially, excluded age as a variable. This prospective laboratory would provide much needed information on aging-related changes in the molecular biology of blood vessels.*

*Recognizing the importance of these three initiatives, during the FY 1990 appropriations process, the Senate Appropriations Committee included report language stating,*

> *"The Committee believes that additional cardiovascular aging research and more research on basic biological age-related changes are important. Two important studies in this area--the relationship between disease processes of atherosclerosis and aging, and aging and the cardiovascular system as well as the development of a laboratory of vascular studies are important initiatives that should be initiated with available funds at the earliest possible time."*

*The American Heart Association (AHA) applauds this Committee's action. However, the partial sequestration and administrative reductions have limited the NIA's "available funds" to begin these initiatives.*

*Resources for specific initiatives in aging research must be sufficient to encourage investigators to make a long term and serious commitment to raising older animals, exposing them to regiments related to atherosclerosis. Atherosclerosis is extremely difficult to study in typical aging animal species like rats. The best animal models for this type of research are pigs and primates, but the research cost for these species is much more expensive than that for more common laboratory animals and demands a major resource allocation to conduct responsible studies.*

*A $5 million increase above the FY 1991 request is required for the NIA to support research in both Atherogenesis and Aging, and Aging and the Cardiovascular System. Another $2 million is needed to develop the Laboratory of Vascular Studies.*

*In FY 1990, the NIA is supporting an estimated $14.240 million in cardiovascular projects. To allow the Institute to adequately fund on-going research and to expand into the essential areas of research in the cardiovascular field described above--Atherogenesis and Aging, Aging and the Cardiovascular System, and the Laboratory of Vascular Studies--the AHA recommends an FY 1991 appropriation of $21.240 million or a $7 million increase for the NIA cardiovascular aging research.*

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## STATEMENT OF THE GERONTOLOGICAL SOCIETY OF AMERICA

Mr. Chairman, members of the Committee, The Gerontological Society of America appreciates the opportunity to submit to you our testimony on behalf of federal support for gerontological research, education, and training programs for the National Institute on Aging and the Administration on Aging.

More people are living longer largely due to improved sanitation, improved public health, and the control of life-threatening (especially childhood) diseases. The effects of these advances have been most noticeable at the earlier ages, where dramatic improvements have increased the probability of surviving beyond the first year of life.

It is only in more recent years that headway has been made in reducing mortality rates at the older ages. A report published by the Office of Technology Assessment states that "more than half of the improvement in life expectancy for the elderly since 1950 has occurred in the past decade."

As years are added to life, research also has begun to look at how to make those added years healthier years. The National Institute on Aging, created only in 1975, has made significant progress with a relatively small budget in developing sound information about what is "normal" aging and what is a result of disease, as well as important knowledge about behaviors and interventions that can lead to a healthier old age.

While aging research is just gathering momentum, the nation is trying to figure out how to deal with a rapidly growing deficit. Domestic program budgets are being frozen or cut back. We are at a crossroads in charting our future course. The budget deficit must be brought under control. Yet, we must not lose sight of the long-term impacts of the means we choose to accomplish this.

Gerontological research and training programs take on increased significance with the expansion of the older population and the simultaneous increases in health care expenditures. The more we learn about what occurs as part of the aging process and what can be attributed to other factors, the better we understand the potential for improving the health of older people through disease prevention and health promotion.

In developing our recommendations for FY 1991, we have tried to keep in mind the tight fiscal constraints under which Congress is operating, making recommendations that maximize the use of existing resources. However, at the same time, we have emphasized the long-term critical role played by these programs and that these "standstill" budgets cannot be continued without major negative consequences.

The President's budget for the Admininstration on Aging includes $1 million for a White House Conference on Aging. Rather than calling for additional monies at this time, The Gerontological Society urges that this money be used to give AoA the resources needed to take on a broader, more key role in aging issues, if a conference is not called.

A very broad mandate is found in Title II of the Older Americans Act and discretionary funds are found in Title IV.

Together, these can be used by the Commissioner on Aging to help the Department of Health and Human Services and Congress get on top of emerging aging-related issues.

In addressing the appropriations for the National Institute on Aging, the only acceptable rationale for maintaining NIA's budget at basically a "standstill" level is that it is a short term "sacrifice."

As the Gerontological Society has testified in the past, the National Institute on Aging has had budget increases in recent years that barely allow the agency to sustain its current program. Increases primarly have been earmarked for specific programs (e.g., research on AIDS and Alzheimer's), but have not significantly increased research in the basic sciences and other important areas of inquiry that could lead to improvements in the health of older persons.

The impact of this spending slowdown is already visible. The growing gap between research opportunities in the field of aging and the lack of sufficient funds to support them is evidenced by fewer approved grants being funded, funded grants being subjected to the practice of "downward negotiations" of between 10 and 14 percent after they are awarded, and research centers being supported at reduced levels. In addition, there remains a serious shortage of trained professionals to care for the health needs of older persons, and the shortages of faculty and other leaders with adequate preparation in geriatrics to train the needed health professionals.

Another critical concern raised in our testimony last year is the deteriorating condition of the infrastructure and resources necessary for carrying out the needed research. These include facilities, equipment, and people. We reported last year that NIA has experienced a 7 percent reduction in staff over the past five years, while at the same time its budget has jumped from $144 million in FY 1985 to $222.9 million in FY 1989.

The deterioration of this country's research facilities is not a popular cause in Congress simply because of the expense involved. However, these facilites are the foundation for conducting research and if an investment is not made soon, no matter how modest, to repair, renovate, and replace existing facilities (not constructing new ones) we will limit our ability to take advantage of future opportunities.

Another issue that threatens the ongoing research effort is the inadequate number of new scientists being trained for future research. Data from a number of sources, including the National Institute on Aigng, the National Academy of Sciences (NAS), and the National Science Foundation (NSF), indicate a current shortage of certain types of scientists and suggest the likelihood of far greater shortages in the near future. Since the training period for becoming a fully qualified investigator is long, it is critical that trainees get into the pipeline as soon as possible to ensure a continual cadre of highly trained scientists.

The important role of research is well recognized and appreciated beyond the research community. A survey conducted by Penn + Schoen Associates in 1989 found that 76 percent of all Americans believe the federal government should make a NASA-like commitment for a program of research to ensure the health and independence of older Americans. In addition, the bipartisan Pepper Commission, in a recent report to Congress, recommended that the federal government "should move aggressively to contain costs and mitigate human suffering by funding a research and development program aimed at preventing, delaying and leading with long-term illnesses and disabilities." The Commission further recommended that the research effort should move toward a funding level of $1 billion annually.

The Gerontological Society sees the Pepper Commission's recommendation as a step in the right direction in recognizing the critical role research plays in addressing escalating health care and human costs related to aging. However, research efforts cannot be limited to diseases. Research efforts must continue to look at the "normal" aging process and ways to maximize successful, healthy aging.

In conclusion, a short term "standstill" budget for gerontological research and training, along with other federal programs, could be tolerated for a longer term gain of a reduced federal deficit and a healthier economy. However, continuing this pattern could have devastating, potentially costly consequences.

## STATEMENT OF THE GERALD AND MAY ELLEN RITTER DEPARTMENT OF GERIATRICS AND ADULT DEVELOPMENT

It is a pleasure to submit testimony on behalf of the National Institute on Aging. As you know, I headed the National Institute on Aging from 1976-1982 and have followed the progress of the Institute with great interest. When the budget of the National Institute on Aging was established, the legislative mandate that Congress set forth required NIA to coordinate research on aging and to disseminate that research as well as serve as the principal entity to conduct and support aging research and research training.

Aging research and training require a substantial investment of resources. Senator John D. Rockefeller as Chair of the U.S. Bipartisan Commission on Comprehensive Health Care (called the Pepper Commission), recognizing the growing needs of the disabled and elderly populations called upon our country to invest $1 billion in research on aging. Yet, the President's Budget request for NIA in FY91 is $248.938 million. About $230 million of the $248 million is earmarked for research on basic disorders and disabilities in later life, to understand aging and promote health, and to identify interventions for special populations. Yet the opportunity exists to fund at least another $175 million for first-rate, high quality research. The consequence of not funding this research results in higher monetary costs now and extraordinarily higher costs in future years. The inability to support researchers also has serious consequences for the development of future researchers as I will discuss later.

The research supported by your appropriation not only focuses upon discovery but application of new knowledge which make real differences in people's lives. New discoveries, new rehabilitation techniques, and new insights into the interaction of aging and function, improve the ability to remain at home and perhaps participate in the community. Research can relieve the stress and burden of caregivers who face the daunting need to care for demented and disabled individuals who can do little, if anything for themselves, but who can not be left by themselves.

The Office of Technology Assessment Government's Advisory Panel on AD has called for $300 million for Alzheimer Disease research and $50 Million for Services Research. With the recent findings in East Boston reported in the Journal of the American Medical Association that there is a 10.3% incidence of Alzheimer Disease among those aged 65 and over, our country is facing a time bomb which will explode by the middle of the next century.

New knowledge through funded research can avert this catastrophe. Research allows us the best of all worlds -- service improvements, perhaps prevention of problems and, ultimately -- cost containment by improving outcomes, deferring problems or avoiding them altogether.

The studies of hormonal treatment for enlarged prostates are an example of how research improves outcomes and cost the system less money. Shortly after I started at NIA, we established research to develop medical treatment for prostrate disease. Although the FDA has not yet approved the hormonal therapy to combat benign prostatic hyperplasia (BPH), drug approaches appear promising in the clinical trials to date. In addition to drugs, other new techniques are also being tested. These are much less costly than the 400,000 prostatectomies for which Medicare pays well over $1 billion per year.

In the area of training, the President's budget calls for only $11.47 million while the need for geriatricians and academic leaders in geriatrics grows daily. At a minimum, the NIA should support 10 Centers of Excellence and spend $32 million on training new faculty and fellows. Training geriatricians MUST become a higher priority in this country.

During the past year, I have served as a senior advisor to the National Academy of Sciences' Institute of Medicine, National Research Agenda on Aging which has received generous grants from the Commonwealth Fund in New York and the Pew Memorial Trust. The committee is ably chaired by Julius Krevans, M.D., Chancellor of the University of California. The report, which should be released this summer, identifies and specifies the compelling need for new knowledge and where the breakthroughs are most likely, in biological, clinical, behavioral and social sciences and health services research. The report should help the Congress, private sector business and the philanthropic community identify research which will enhance the quality of life and the care available for the growing numbers of older people. The research should also provide new knowledge of how and why we age.

I am concerned about the clarity of the relationship between the NIA and the new Agency for Health Care Policy and Research which has received a substantial increase in appropriation. The Research on Aging Act of 1974 was clear that NIA should play a critical role in coordinating research on Aging and the Aged in the Health and Human Services Agency. Since AHCPR is dedicated to controlling Medicare spending and since the majority of Medicare beneficiaries are elderly people, it is critical that NIA and AHCPR's activities be well defined and the research be coordinated.

The NIH research budget has experienced an unprecedented decline in the percentage of approved grants which are actually funded. It appears that in FY91, NIA will only be able to support about 17% of new and competing approved grants. Thus, physician scientists and others in the gerontology and geriatrics community, who develop and submit grant proposals which are recognized as outstanding, and are approved through the rigorous study section peer review process, receive no funding. These individuals are turned away, perhaps forever, from studying aging. Our unwillingness to fund more research also limits our country's ability to develop new knowledge of how to answer many mysteries and miseries of aging.

Historically, fields within the National Institutes of Health have developed and gained momentum with Centers of Excellence. Centers allow newly emerging fields to take advantage of economies of scale of scarce resources. Centers concentrate -- animal models, animal colonies, faculty, medical fellows, human populations and all the other knowledge and materials necessary to encourage research in the new field -- in one place. The centers and supported research which naturally flows from the Centers also sends a signal that the new field is important and intellectually demanding.

I urge you to allocate enough money to support ten centers of excellence over the next five years just as the legislation submitted by Senator Jim Sasser has recommended. Currently, the National Institute in Aging has two Centers of Excellence. I ask you to support geriatrics' development as Congress was wise to do in the past e.g. with the National Institutes of Heart and Cancer. These institutes have proven that the investment in Centers and the development of research agendas, does promote new knowledge, treatments and relief for millions. We only have to note the 30-40% reduction in deaths for heart disorder and strokes to understand the impact of research on the lives of all of us.

Finally, I know you recognize the importance of dissemination of information to the public. Health promotion and disease prevention encourage individuals to remain healthy -- the best cost containment. But NIA must have the resources to disseminate its knowledge to elderly people.

# NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE

## STATEMENT OF THE HUNTINGTON'S DISEASE SOCIETY OF AMERICA

Mr. Chairman and the members of the Subcommittee, thank you for this opportunity to present our written statement regarding the FY 1991 appropriations for the National Institutes of Health (NIH):

### Our Vision at HDSA

Can you imagine actually overcoming a disease that people once thought would never be conquered? Can you imagine how many people were touched by Huntington's Disease (HD) over the millennia -- who died, whose families suffered through it with them and who often didn't even know what they had? Can you imagine -- just for a moment -- what it would mean to those thousands of Americans currently suffering from this complex disease, and the future generations destined for the same suffering, if a cure were discovered? Imagine -- just for a moment -- what a wonderful thing this would be.

### Some Facts About HD

- Huntington's Disease is an inherited, progressively degenerative brain disorder which results in a loss of both mental capability and physical control. Over a period of 10-25 years, the ability to think, to speak, and to walk diminishes gradually, leading to total incapacitation and death through complications such as infection, pneumonia, or heart failure.
- Presently, there is no effective treatment. Although medications can give some partial relief, no drug can stop the disease's steady progression.
- It is estimated that up to 1 in 5,000 live births in the U.S have HD.
- Today, well over 125,000 people in the U.S. are known to be at-risk.

- HD transcends the boundaries of sex, age, race and ethnic group.
- HD does not skip generations. If a parent has the disease, there is a 50% chance that each child will have it.
- Care is very expensive.
- HD is inevitably fatal -- there is no known cure.

**Who We Are**

The Huntington's Disease Society of America is dedicated to:

- The eradication of Huntington's Disease.
- The care of people with HD.
- Assistance for Huntington's families.
- Educating the public about the disease.

**What We Do**

This movement, begun by Marjorie Guthrie in 1967, the year of the tragic death from HD of her husband, folksinger Woody Guthrie, has evolved over the years into a dynamic partnership between a professionally staffed headquarters office in New York City and hundreds of grass-roots volunteers in chapters and affiliates from coast to coast.

It is this partnership that enables HDSA to reach out with a helping hand to Huntington's families everywhere; to field a network of social workers who are available for counseling and practical guidance; to run support groups for care-givers and family members; to advocate the needs and rights of people with Huntington's Disease; and to distribute, through newsletters, booklets, pamphlets and audiovisual materials, accurate and up-to-date information on HD.

Of course, it is research which is the principal source of hope and encouragement for those affected by or at-risk for Huntington's Disease. This is why HDSA devoted over $250,000 last year - almost a quarter of its budget - to the funding of 10 carefully selected research projects, and why its research programs will remain a critical priority until a cure for Huntington's Disease has been found.

**Research -- The Challenge**

In 1983 researchers at the New England Huntington's Disease Center Without Walls discovered a DNA marker for the HD gene, enabling many at-risk people to take a presymptomatic test to discover whether or not they will develop the disease. This remarkable breakthrough would not have been possible without funding from the National Institute of Neurological Disorders and Stroke (NINDS).

The search for the HD gene itself continues. The quest for a cure is bringing us closer each day. By stimulating pioneering medical research, HDSA is playing a central role in making this dream a reality.

Since the HD research model is a paradigm for other late-onset genetic disorders such as Alzheimer's Disease, bipolar manic depression, and schizophrenia, the decrease in funding for approved grants will have a profoundly negative effect on the rate of scientific progress in conquering diseases affecting millions of Americans. A decreasing pool of young scientists would eventually impact on the NIH research structure and, in particular, on the momentum that has now been established for HD. If this were to happen, attempts to reassemble this research effort would prove difficult and again require years in development to achieve the current level of productivity.

**Summary and Recommendations**

In conclusion, Mr. Chairman and members of the Subcommittee, the Huntington's Disease Society of America respectfully requests an increase in biomedical research funding through the National Institute of Neurological Disorders and Stroke (NINDS) of NIH.

The NIH appropriations act for FY 1990 will not provide the funding to NINDS necessary to sustain the current research momentum. Indeed, the $30.5 million allotted to HD research for 1990 will at best fund only 20% of approved grants in all programs of NINDS. The President's proposed level of funding for FY 1991 is $31.157 million, a 2% increase that fails to take into account the effects of inflation. This low level of funding comes at a time when Congress has recognized the important objectives and opportunities of neuroscience research and has declared the 1990's as the "Decade of the Brain."

Because fewer grants can be funded at the current level, there is a fear that diminishing governmental commitment to basic neurological research will actually lead to a "brain drain" of talented, highly specialized scientists who will no longer find support for their work. Furthermore, the current research momentum threatens to fade. Our goal is thus twofold: to ensure that new grants are funded, and to guarantee funding for existing projects.

NINDS has requested a $200 million increase in order to keep up with the scientific achievements of the past decade by providing funding for grants in important research areas such as Huntington's Disease. For HD research, we would like to see an increase of 5% per year, above inflation considerations, as opposed to the current 2% increase.

Mr Chairman and members of the Subcommittee, in this first year of the "Decade of the Brain", we believe that continued support for HD research should be a high priority.

Thank you very much.

## STATEMENT OF THE AMERICAN HEART ASSOCIATION

*The American Heart Association (AHA) is dedicated to the reduction of disability and death from cardiovascular diseases and stroke. We work in active partnership with related federal research, education, and prevention programs, including the National Institute of Neurological Disorders and Stroke (NINDS). Our comments and FY 1991 funding recommendation for the NINDS follow. Due to the importance of animal research, this statement includes comments and funding recommendation for the National Institutes of Health's (NIH) Division of Research Resources (DRR).*

### NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE (NINDS)

*Stroke, a cardiovascular disease, occurs when a blood vessel bringing oxygen and nutrients to the brain bursts or is clogged by a blood clot or some other particle. Deprived of oxygen, nerve cells in the affected area of the brain cannot function and die within minutes. The devastating effects of stroke are often permanent because dead brain cells are not replaced.*

*Stroke is the third largest cause of death in America. Each year stroke strikes an estimated 500,000 Americans, killing about 150,000. Survivors number about 2.060 million, but many are left with mental and physical disabilities. Stroke is a major cause of disability, accounting for about half of all patients hospitalized for acute neurological disease. In 1990, stroke-related health care will cost an estimated $14.5 billion in medical expenses and lost productivity.*

*However, from 1977 to 1987 the age-adjusted death rate from stroke fell by 37.3 percent. The downward trend is related to the identification and treatment of the major risk factors for stroke.*

*Progress has been made in stroke diagnosis and treatment. Advances in technology make it possible to examine how the brain looks, functions, and acquires blood supply. Positron emission tomography (PET), computerized axial tomographic scan (CT or CAT scan), magnetic resonance imaging scanning (MRI), and radionuclide angiography (nuclear brain scan) provide vital information to pinpoint, understand, and treat brain damage caused by stroke. New treatment methods have been developed that can be administered immediately after a stroke to minimize effects.*

*The stroke age-adjusted death rate has declined, but some epidemiologists believe the number of new cases of stroke is again starting to rise. Several factors may attribute to the rising incidence of stroke, including enhanced technology detecting less severe strokes and an aging population.*

*The National Institute of Neurological Disorders and Stroke (NINDS) is the Federal focal point for neurological research, including research on the cause, treatment, and prevention of stroke. NINDS stroke research programs consist of a wide range of studies by individual researchers in facilities across the country and by teams of scientists in NINDS-supported stroke and positron emission tomography (PET) research centers. Mainly due to the encouragement of the NINDS, stroke has become a key focus of study at many of our nation's outstanding research institutions.*

*The NINDS Stroke and Trauma Division maintains 14 cerebrovascular clinical research centers which constitute the primary force of its stroke research program. As a result of studies in these facilities,* *the disease process of stroke is becoming more clearly defined. Also, NINDS-supported researchers conduct multi-year studies on the stroke population to determine long-term damage and treatment effectiveness. Animal studies significantly enhance knowledge about stroke.*

*Stroke prevention is the main goal of stroke research. Research promotes stroke prevention, brain function recovery, and an improved quality of life. Highlights of some recent and proposed NINDS stroke studies, subject to the availability of appropriations, follow.*

- *A risk factor study is focusing on elevation of blood sugar levels. Concentrating on the unique mechanisms that control blood flow in the brain and brain metabolism, investigators have noted a relationship between increased blood sugar and stroke development.*
- *The function of platelets, elements in the blood that help form blood clots, is being examined in an effort to interpret the process of blood clot formation that can cause stroke. Additional research is focusing on the role of platelets in the formation of atherosclerotic plaque formation.*
- *Two studies are being conducted to clarify the disproportionate incidence and death rates from stroke between black and white Americans. Blacks have a 60 percent higher risk of death and disability from stroke than whites. In an attempt to explain this difference, researchers are examining different aspects of stroke risk factors, including diet, smoking, and high blood pressure.*
- *Research to restrict brain damage during a stroke is being conducted at multiple sites. The effects of immediately cooling the brain to prevent stroke-related brain damage has shown promise in the laboratory. The study of intercellular molecular damage, caused when oxygen is reintroduced to the brain after stroke, is being examined at another location.*
- *Clinical studies have revealed the possibility of a wider window of opportunity in treating some stroke victims before permanent brain damage occurs. Tissue plasminogen activator is a technique for restoring blood flow and oxygen to the brain during stroke. The safety and the optimal dose of t-PA for stroke therapy is being evaluated. T-PA will be a subject of a larger clinical trial.*
- *A major multicenter clinical trial which evaluated whether aspirin or warfarin, a drug that can prevent blood clotting, would prevent strokes in victims with atrial fibrillation, a common type of irregular heart beat in older persons, showed that these drugs reduced stroke incidence by 81 percent. Another clinical trial is being planned to evaluate the effectiveness of heparinoid, a derivative of a widely-used anticoagulant, heaprin, in preventing new strokes caused by blood clots.*
- *Two multicenter trials are assessing the efficacy of a widely-used surgical procedure, carotid endarterectomy, for stroke prevention in symptomatic and asymptomatic patients. Carotid endarterectomy, a surgical procedure to remove atherosclerotic buildup of plaque from the carotid artery, in conjunction with medical treatment, is being compared to medical treatment without surgery.*

*The President's FY 1991 budget contains $512.212 million for the NINDS. This 4.45 percentage increase over the FY 1990 appropriation does not sustain adequate growth, stifling the NINDS' ability to continue and to initiate many promising stroke research programs. The impact of the budget follows.*

- *Only 405 competing research project grants would be funded, compared to 415 in FY 1990, at an* *award rate of 16 percent of approved grants, down from 20 percent in FY 1990. The projected number of FY 1991 competing grants, 405, assumes a 25 percent reduction in each grant.*

- *Research centers would be held constant.*
- *Research contracts and individual and institutional training awards would be straightlined.*

*Beginning in FY 1987, NINDS placed a stronger emphasis on stroke; but, since then, growth has been much smaller. In FY 1990, funding for stroke research increased by only 3.19 percent over the FY 1989 level. Under the President's request, funds for stroke research would be increased by 4.60 percent over the FY 1990 level. This proposed level of support troubles the AHA.*

*We now stand on the threshold of great discoveries in stroke prevention and rehabilitation. The NINDS must receive sufficient funds to maintain research momentum and to initiate programs with the potential to decrease stroke incidence and its debilitating consequences.*

*Acknowledging neuroscience advances and recognizing the opportunity for further achievements, Congress and the President have designated the 1990's as the Decade of the Brain. A FY 1991 appropriation of $691.421 million, a 41 percent increase over the FY 1990 funding, will allow the NINDS to implement fully priorities and programs for the first year of the Decade of the Brain, outlined in the National Advisory Neurological and Communicative Disorders and Stroke Council's congressionally-requested report, Decade of the Brain: Answers Through Scientific Research.*

*During the height of research opportunities in cancer and cardiovascular diseases, Congress provided both the National Cancer Institute (NCI) and the National Heart, Lung, and Blood Institute (NHLBI) with resources to exploit advances. Between the years of 1971 and 1976, the appropriations for these institutes grew 241 percent and 98 percent, respectively. The corresponding growth for the NINDS, excluding funds for communicative disorders, was 45 percent. The neurosciences is now at the point where cancer and cardiovascular research was twenty years ago. According to the aforementioned report, "Our Nation stands on the threshold of enormous opportunities in the neurosciences. The foundation for future advances has been laid, and the potential exists for incalculable reductions in the human and economic tolls exacted by neurological disease and communicative disorders. The immediate and long-range benefits of research cannot be overestimated. The only question that remains is whether we as a Nation have sufficient foresight and will to exploit these research opportunities." An FY 1991 NINDS appropriation of $691.421 million will allow the Institute to "exploit research opportunities."*

## *DIVISION OF RESEARCH RESOURCES (DRR)*

*The DRR, the National Institutes of Health's focal point for providing resources to extramural institutions' biomedical research, directly affects NIH-supported biomedical research at facilities throughout this nation. The DRR develops, sponsors, and administers research resources through multicategorical programs of specialized research facilities and environments.*

*Animal research constitutes a crucial component of biomedical research. The AHA is alarmed that the President's proposed 5.33 percent decrease in funding is below the DRR's FY 1990 appropriation. The AHA's concerns about two of the DRR's six extramural programs follow.*

### *Laboratory Animal Sciences and Primate Research Program (LASPR)*

*LASPR supports the NIH's funded research projects grants which use laboratory animals. LASPR's seven Regional Primate Research Centers provide specialized resources and suitable research environments for a wide range of basic and applied biomedical studies. Washington Regional Primate Research Center investigators have made strides in developing an improved artificial blood vessel to bypass or replace portions of arteries blocked by atherosclerosis, a risk factor for stroke and heart attack. Studies indicate that this more porous substance may be a better substitute than a blood vessel taken from another body part or made from another material.*

*Also LASPR sustains research and diagnostic laboratories, educates specialists in laboratory animal sciences, develops animal models for use in biomedical research, and enhances laboratory animal facilities supporting NIH research. Moreover, LASPR helps the NIH Director's office create guidelines for the humane care and use of research animals. LASPR also acts as a liaison to animal welfare and professional societies.*

*The President's FY 1991 budget recommends $68.563 million for the LASPR program. This one percent increase over the FY 1990 appropriation represents a slight growth in AIDS-related research only. The President proposes to hold constant for non-AIDS activities Regional Primate Research Centers. Resources for training in the Laboratory Animals Sciences Program, animal facilities improvement grant program, and research projects would be identical to the 1990 level.*

*The request for the LASPR Program does not meet current and anticipated needs. LASPR's resources must be sufficient to cover the Program's expanded duties and responsibilities under the 1985 Animal Welfare Act Amendments. The animal facilities improvement grant program helps biomedical research facilities comply with the Animal Welfare Act and the Public Health Service policy on humane care and use of animals. This assistance comes in the form of support for caging sanitation equipment and facility renovation. So LASPR can meet its critical needs, the AHA recommends an FY 1991 appropriation for DRR of $411.268 million, a 22 percent increase over FY 1990.*

*Animal facilities and properly trained animal medicine personnel are a necessary aspect of all biomedical research activities. Moreover, proper facilities and healthy animals help to insure reliable research results. The AHA's recommended appropriation for the DRR, $411.268 million, will only begin to control animal disease and to improve the wide-spread deterioration in a majority of the research animal facilities at biomedical research institutions across the Nation.*

### *Biomedical Research Support Grant (BRSG) Program*

*The BRSG Program provides individual facilities with a pool of flexible funds for particular projects, determined by the respective institution, not generally met by other support programs. By allocating these* *funds to individual projects, DRR provides the facilities with the flexibility to meet unanticipated needs and emerging opportunities.*

*For the past several years, the Administration has proposed to terminate the BRSG Program, but Congress has consistently restored funds. While the President's FY 1991 budget contains resources for this program, the request, $17.700 million, is 60 percent below the FY 1990 appropriation. The AHA's recommended FY 1991 appropriation for the DRR, $411.268 million, would allow the BRSG program to meet current needs.*

# NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT

## STATEMENT OF THE INTERNATIONAL RETT SYNDROME ASSOCIATION

I am Kathy Hunter, founder and President of the International Rett Syndrome Association, the only national support and advocacy organization for the disorder known as Rett syndrome. The mission of the IRSA is to support and encourage research efforts to find a cause, treatment and cure for Rett syndrome; to increase public support to families of children with Rett syndrome; and to provide emotional support to families of children with Rett syndrome.

Rett syndrome has occurred only in girls to date. Development appears normal up until 6 to 18 months of life. The child then begins a regression that causes a loss of social, motor and cognitive skills leading to severe mental retardation and physical disability. Approximately one half of those with Rett syndrome are able to walk independently, and mobility decreases with age in those who do walk. A significant number of those affected have epileptic seizures, breathing abnormalities and curvature of the spine. Purposeful use of the hands is lost, and the child makes almost constant repetitive movements which include washing, clapping, tapping, wringing and mouthing of the hands. While head circumference is normal at birth, the child's head growth slows abnormally with age. Intellectual development remains in the severely to profoundly retarded range.

Rett syndrome was first discovered in Europe over 25 years ago. However, it was virtually overlooked in the American medical community until late 1983, when the first English language report appeared in a prestigious medical journal, The Annals of Neurology. If research had concentrated on the cause over two decades ago, we might today know of an effective treatment that would lessen the devastation of this disorder.

At the International Rett Syndrome Association, need always exceeds resources. We must meet the enormous need for information, referral, networking, advocacy and counseling. While funding research is an important goal, it must be recognized in light of the total resources of the organization. The IRSA is doing the best it can to stimulate research on Rett syndrome. Unfortunately, our ability to raise funds from private sources is limited, and the major monies must come from NIH.

Research on Rett syndrome has come a long way in the last few years since it was first identified in the United States. Collaborative efforts have been underway between the NINDS and the NICHD since 1985, when the first scientific meeting was held at Johns Hopkins University to delineate the syndrome as a specific disease. Three outstanding research centers at Johns Hopkins University, Baylor College of Medicine and the University of Massachusetts received grants from the NIH to investigate Rett syndrome, and all have made excellent progress.

These studies have revealed important information about the clinical picture of Rett syndrome and its underlying pathology. Their continued funding is critical and immediate to our need to further understand this disabling disorder. We are no longer on a fishing expedition - the waters are clearer and our search is more concentrated. We are closer than ever to making a major breatkthrough that will put an end to Rett syndrome.

Two recent simultaneous reports of mutations on the X chromosome have given strength to the consensus that Rett syndrome is genetically determined. These reports indicate that a critical region in the general neighborhood of the Duchenne Muscular Dystrophy gene is abnormal in Rett syndrome. There is no other region of the X chromosome that has been studied so thoroughly, and all of the mapping data provided by the DMD research can now be applied to the study of Rett syndrome. We are now closer to an answer to the most fundamental question in Rett syndrome, the cause. Baylor College of Medicine has done outstanding work in the field of genetics in Rett syndrome, and will continue their efforts to find a biological marker. The RETT Center at Baylor College of Medicine has now studied 75 girls as they enter the third year of a five year award, and has developed a broad understanding of the clinical spectrum of Rett syndrome, the neurophysiological correlates regarding EEG, sleep and breathing patterns, and communication skills. A comprehensive study of epidemiology of Rett syndrome in the state of Texas is also ongoing. This center recently submitted a request for supplemental funding ($750,000+) during the last 30 months of the present award to expand studies on exciting new leads.

Johns Hopkins/Kennedy Institute has had the opportunity to do clinical studies and several post-mortem examinations in Rett syndrome in an attempt to understand its neurobiological and neuropathological basis. Six of the nine post-mortem specimens became available only during the second and third year of the current grant, so these studies are still in progress. Additional funding will enable this research center to further explore the hypothesis that Rett syndrome is actually an infantile form of Alzheimer's/Parkinson's Disease, due to similar changes that occur in the brain. Thus, effective treatment may allow us to alter the disease process in other disorders. 47 patients with classical Rett syndrome have been evaluated fully in studies that have included many clinical, physiological, behavioral, biochemical and genetic aspects. Continued funding will enable this research center to complete the full set of clinical and laboratory studies in 100 patients, and will allow for completion and expansion of post-mortem studies. This research center at Johns Hopkins/Kennedy recently submitted a renewal application for a three year program project to continue their studies.

The University of Massachusetts is in the third year of a four year study. The goal of this project is the identification of genetic and epigenetic factors that regulate neuron-specific gene expression. The model under study is the gene encoding neuron-specific protein Synapsin I, believed to play a role in the regulation of neurotransmitter release. Substantial progress has been made in characterizing the structure and expression of this gene, and cooperative studies with the Baylor group are in progress.

Of great concern is the reduction in funding of approved grants at the NIH, which is expected to be only 12%

at NINDS and NICHD in fiscal year 1990. This means at those institutes, 88% of APPROVED research grants will NOT be funded, and vitally important research on the scientific frontier will be lost.

The IRSA supports the recommendation of Friends of NICHD for funding in the amount of $635,306,000 for FY 1991 to the National Institute of Child Health and Human Development. This recommendation will allow NICHD to alleviate current budgetary constraints and to fulfill its charge more appropriately.

The IRSA supports the recommendation of the National Research Committee for funding to the National Institute of Neurological Disorders and Stroke of $691,421,000 for FY 1991. This figure provides for an increase in total research grants, training programs, intramural research, research and development contracts and program direction.

In summary, we are far closer to understanding Rett syndrome than a few years ago. Pioneering studies have been carried out at three outstanding research centers. Continued and increased funding will allow these centers to learn more about the cause, which may lead to effective therapies and treatments that will enable the child with Rett syndrome to enjoy a more normal life. We anticipate the continued support of the Committee to ensure that research funds will be made available to support projects of scientific merit in the field of Rett syndrome. Research is our only hope for a better life for our children. If we CARE today, we can CURE tomorrow.

# STATEMENT OF THE MARCH OF DIMES BIRTH DEFECTS FOUNDATION

The March of Dimes Birth Defects Foundation is submitting this testimony in support of increased federal funding for health research and preventive health services that improve maternal and child health.

The March of Dimes works to prevent birth defects, and the related problems of low birthweight and infant death. One way in which the foundation pursues its mission is by funding biomedical research to help us understand human development and the causes and treatment of birth defects, low birthweight, and preterm delivery.

For the March of Dimes, prevention also means ensuring access to health care for pregnant women and infants through educational and community service programs. Given the limited impact that any one organization can have in this area, the March of Dimes is a strong advocate for federal funding of biomedical research and for federal and state funding for preventive health care for mothers and children.

As a nation, we must make prevention our top priority. Our fiscal constraints demand that we spend money wisely and effectively. Biomedical research and cost-effective health care programs for mothers and children should be top funding priorities for Congress. We know that every dollar spent on prenatal care can save over three dollars in neonatal intensive care costs. We know that each dollar spent on immunizations for children saves ten dollars by preventing disease. We need to ensure that these effective programs are available to all who need them.

## HEALTH RESEARCH

Biomedical research can help prevent birth defects and improve maternal and infant health. The nation's primary source of funding for research on maternal and child health is the National Institute of Child Health and Human Development (NICHD). When NICHD was added to the National Institutes of Health in 1962, the nation's infant mortality rate was 25.3 per thousand. Medical technology developed through NICHD and other sources has been largely responsible for reducing our infant mortality rate to 10.1 deaths per thousand live births in 1987. This is an important decline, but we still rank 20th among industrialized nations in preventing infant death.

Like the March of Dimes, NICHD is concentrating on reducing low birthweight as a way to reduce the incidence of infant death and disability. One important component of the NICHD program is research carried on by the Perinatal Emphasis Research Centers or PERCs. There are six PERCs, each of which focuses on a different area of perinatal research. High-risk pregnancy, premature labor and birth, and AIDS are among the research areas. Adequate funding is essential if we are to make further progress in understanding and preventing birth defects and infant mortality. Yet NICHD is expected to fund only 20 percent of approved grants in FY90. Maintaining even this number of grants means that each award may have to be reduced by 12 to 15 percent of recommended funding. The FY91 Administration budget would not significantly increase awards, funding only 22 percent of approved grants.

Similarly, funding for PERCs and other research centers is being reduced by an estimated 17.1 percent in FY90 and by an estimated 21.6 percent in FY91. NICHD, and the National Institutes of Health as a whole, must receive increased funding if we are to maintain a top notch biomedical research program.

## HEALTH SERVICES

In the area of health services for mothers and children, we are seeing progress in our effort to ensure access to health care for mothers and their children.

The importance of prenatal care and child health care to ensuring the productivity of our next generation has been recognized by Congressional leaders and such diverse groups as the Council on Competitiveness, the Committee for Economic Development, the American Agenda, the National Commission to Prevent Infant Mortality and the Institute of Medicine. A number of discretionary health programs work together to improve maternal and child health. Community health centers provide prenatal care to more than

150,000 pregnant women annually. Funding from the Maternal and Child Health Block Grant is used to serve hundreds of thousands of low income and uninsured pregnant women and millions of children. The Childhood Immunization Program helps fund the vaccination of about half of our children and serves all families by monitoring vaccine use as well as incidence of disease and by maintaining a vaccine stockpile. Health professionals, funded through the National Health Services Corps, staff clinics in underserved areas.

These programs are interrelated and often serve the same populations. Thus no one program can be increased at another's expense. All must be fully funded to maximize their ability not only to complement one another, but also to maintain and improve maternal and child health in this country.

At the same time, our success in improving maternal and child health is being threatened, particularly by substance abuse and AIDS. We must strengthen our core maternal and child health programs. A growing number of pregnant women continue to use illicit drugs, which threatens the progress we have made in reducing low birthweight. Nationally, it is estimated that each year in the United States up to 375,000 babies may be affected by in utero exposure to drugs.

The March of Dimes is deeply concerned about the effects of substance abuse on women and their children. Substance abuse during pregnancy can lead to spontaneous abortion, preterm delivery, birth defects and impaired brain function and intelligence.

Women who use drugs are also at exceptionally high risk for sexually transmitted diseases, including AIDS. By 1991, there will be an estimated 10,000 to 20,000 cases of pediatric AIDS. About 80 percent of all reported pediatric AIDS cases -- currently more than 900 children -- can be traced to HIV-infected parents. Pregnant women with HIV infection pass the virus to their fetuses about 50 percent of the time. The growing number of children with AIDS adds new burdens to the already stretched federal programs, particularly NIH research, community health centers, and Medicaid.

## SUMMARY AND RECOMMENDATIONS

The March of Dimes has worked with other national organizations to develop recommendations for federal funding of critical health research and services programs.

The March of Dimes Birth Defects Foundation joins with the Coalition for Health Funding in recommending funding of at least $9.2 billion for the National Institutes of Health, and $635.3 million for the National Institute of Child Health and Human Development.

Together with 19 other national groups interested in maternal and child health, the March of Dimes supports:

- Full funding of the Maternal and Child Health Block Grant at $686 million.
- An additional $80 million in funding for the Childhood Immunization Program, to ensure that all children are adequately vaccinated.
- An additional $85 million for basic program of the Community and Migrant Health Centers, and an additional $5.9 million for the infant mortality initiative.
- An additional $79 million for field placement, scholarship and loan programs of the National Health Service Corps.

As a member of the Pediatric AIDS Coalition, the March of Dimes calls for:

- $57 million for model prevention, education and treatment projects for substance abusing pregnant women, conducted through the Office of Substance Abuse Prevention.
- $15 million to implement the Abandoned Infants Assistance Act, which will provide foster care for drug addicted and HIV positive infants who are abandoned in hospitals.
- $30 million for pediatric AIDS health care demonstration grants.

Federally funded programs for mothers and children have been and continue to be effective. However, we must recognize that millions of women and children still lack access to health care. We must continue our commitment to research and health services that benefit our nation's future generations.

# NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES

## STATEMENT OF THE JOSLIN DIABETES CENTER

Goodday. My name is Dr. Kenneth E. Quickel, Jr. I'm president of Joslin Diabetes Center in Boston, Massachusetts. As chief executive of the nation's oldest and largest diabetes treatment and research instititution, I want to convince you how important it is to fund research to cure or prevent diabetes.

At Joslin we see over 20,000 people with diabetes each year... Many of these people, happily, are living well with their disease.

Many others are blind or going blind...losing kidneys, having amputations and dying of heart attacks and strokes. Many of the 11 million Americans with diabetes are in this condition because we don't know how to cure or prevent this disastrous disease.

Take a patient at Joslin named Pam. She's in her 20s, bright, attractive...and blind for the past several years because of her diabetes. Several years ago she had a kidney transplant too. Her brother has diabetes as well, and has had a kidney transplant too. Pam works, she's athletic, she dates. She'd like to have children someday, but a pregnancy could threaten her life because of the problems here diabetes is causing.

Diabetes kills or contributes to the premature death of 150,000 people every year. Every year diabetes kills three times as many Americans as were killed during the entire Vietnam War.

Diabetes is the leading cause of new blindness in adults. People who have the disease are 17 times more prone to kidney disease; 50 times more prone to gangrene; twice as likely to have a heart attack or stroke. It's a hidden killer that often causes these more visible disasters.

The annual price tag to the American public for diabetes is $20 billion. A major piece of that cost is paid by the federal government, and ultimately the individual taxpayer, through Medicare, Medicaid, and other programs.

Diabetes is largely hereditary. Look at Pam and her brother. Researchers believe that not only is their diabetes caused in part by a genetic link, but that their tendency to develop diabetic kidney disease is connected through heredity as well.

A proposal receiving widespread support here on the Hill suggests that $50 million be dedicated specifically to identify the so-called diabetes genes. It's important research, but I would support this initiative only if this $50 million can be provided without detracting from other equally important diabetes research projects.

At Joslin, and a few other research centers around the country, we're getting closer to preventing the type of diabetes Pam and Paul via another route. Researchers at Joslin use a special blood test to screen family members of someone with juvenile diabetes. This test can tell who will develop the disease as many as 8 years before symptoms develop.

A person identified through this testing program will develop diabetes, unless researchers find a way to stop that from happening. At Joslin alone, we have identified hundreds of pre-diabetics. Thousands more exist all around the country. They will all develop diabetes unless we learn how to prevent it.

The U.S. currently enjoys great international preeminence in the field of biomedical research and in diabetes research in particular. In recent years trained teams of researchers at Joslin and elsewhere around the country have brought us to the threshold of important new knowledge in diabetes. If their work cannot be funded, these teams will gradually lose their momentum and disappear, their promising efforts lost.

I realize how often you hear the call for more funding for this program or that. Your task is not an enviable one. But last year in this country we spent $1.7 billion on Nintendo, $1 billion on popcorn, $700 million on peanuts and $580 million on the entire NIDDK budget. We know you have no control over how Americans spend their non-tax dollars. But looking at those figures, it's not unreasonable to want to rally the American public -- and you as their representatives -- around far more pressing needs for money than video games and junk food.

Since 1987, the amount of money allocated to NIDDK, when adjusted for inflation, has actually declined each year. Yet the incidence of diabetes is increasing by 6 percent per year.

If the polio vaccine were not developed in the 1950s, today the costs of that disease annually in the U.S. would be over 30 billion dollars. This one discovery alone has paid for all of the NIH budgets since that government agency was funded.

If you are looking for a way to save another $20 billion a year, much of it spent by the federal government, simply fund the research necessary to wipe out diabetes !

We need to find a cure for diabetes. The savings in lives, human suffering ... and dollars, will be immense. Thank you for giving me the opportunity to speak to you on this vitally important subject. If you have any questions I would be happy to answer them.

# STATEMENT OF THE INTERSTITIAL CYSTITIS ASSOCIATION OF AMERICA, INC.

Honorable Chairman and Committee Members:

Women have made much progress in many areas. Unfortunately, as a recent GAO audit has revealed, equitable research funding by the National Institutes of Health has eluded us. Nowhere is the disparity between male and female research funding greater than in the field of urology.

Interstitial cystitis (IC) is an extremely serious disease. An NIH sponsored epidemiological study indicates that the disease affects approximately 500,000 Americans, mostly women. It strikes in the prime of life and there is no cure or effective treatment. IC costs its victims $1,700,000,000 in medical costs and lost wages per year and according to an NIH questionnaire, the quality of life is clearly below that of end stage kidney patients on dialysis.

In spite of NIH's own statistics and our efforts spanning more than 6 years, no significant progress has been made in obtaining NIH sponsored research. We have not made inroads in securing a fair share of the NIH urology budget because of a funding system that lacks disease specific planning and that allows the research community to set their own priorities based on interest, rather than the needs of society. That the needs of disease victims are not represented in the funding process becomes self-evident with the GAO audit that has determined that only 13% of the NIH budget addresses the health needs of women. In addition, it is estimated that another 20 million Americans are unrepresented because they suffer from orphan diseases.

Nowhere is the gender gap greater than in the NIH Division of Urology. This division deals with all diseases of the lower urological tract with the exception of cancer. Although we have been led to believe that urological disorders affect mostly men, a review of NIH's epidemiological data reveals that this perception is false. With the exception of bladder and prostate cancer (which are funded by the Cancer Institute), female urological disorders* predominate according to all criteria: They exceed in:

- **Total death rate**
- **Total population**
- **Total hospitalizations**

Although benign prostatic hyperplasia (BPH) is the most common surgery in the field of urology, hospital admissions for predominantly female disorders still exceed those of men. Unlike male disorders such as BPH and urinary calculi, disorders of women tend to be chronic, thereby draining the individual both emotionally and financially. The perception of male predominance in urology is based on some very misleading statistics; for example: We have been led to believe that 1 out of 4 men suffers from BPH. However, an accurate statement is that the patient population of BPH and interstitial cystitis is equal. Because BPH can be treated and cured, no more than 482,000 persons suffer from BPH each year and this figure remains constant. Additionally, we have been led to believe that there are enormous economic costs for male disorders. What the statisticians do not tell us is that these figures are due to the fact that men earn more than women. The economic cost of a disease is composed of direct medical costs and lost productivity, with the latter generally being the largest factor. The following data was taken off an NIH chart used to calculate lost productivity:

**Present Value per Person (1985)**

| | Under 15 | 15-24 | 25-44 | 45-64 |
|---|---|---|---|---|
| Male | $214,133 | 259,499 | 235,489 | 82,225 |
| Female | 126,666 | 136,152 | 115,044 | 31,438 |

Now that we have established the seriousness of interstitial cystitis as well as other diseases of women, let us examine the NIH urology budget:

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* Note: A disease has been classified as either male or female if it affects one sex greater than 70% of the time.

|  |  |  | % of Urology Budget |
|---|---|---|---|
| **Male Disorders**<br>BPH, stones, male sexual dysfunction* |  |  |  |
| Incidence/yr.: | 1,482,000 | NIH $ 8,245,817 | 71% |
| Expenditure per person = $5.56 |  |  |  |
| **Female Disorders**<br>Interstitial cystitis, infection, incontinence, neurogenic bladder** |  |  |  |
| Incidence/yr.: | 15,500,000 | NIH $ 1,470,338 | 12% |
| Expenditure per person = 9¢ |  |  |  |

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* Note: The incidence of male sexual dysfunction is unknown.

** No accurate data on the incidence of incontinence and neurogenic bladder is available. The estimate of a combined total of 7 million persons is conservative.

The remaining 17% of the urology budget is spent on basic research and other disorders affecting both men and women.

In the area of interstitial cystitis we have had a battle royal with NIH and competing medical interests for every research penny. These vested medical interests are well represented on NIH boards and committees. We, however, only have you to represent us. IC is presently receiving $915,722, not the 1.6 million claimed by NIH. Research on IC has recently been surpassed by studies on male sexual dysfunction which is now funded at the level of $1,126,862.

Last year, after 6 years of prodding, NIH issued its very first IC specific Request for Applications (RFA). We were promised a total of 1 million in funding for fiscal year 1989, $850,000 for the RFA and $150,000 for the National Registry. The results are in and they are devastating. Although a total of 13 excellent proposals were received by NIH in 1989, only 2 were funded for a grand total of $361,121. Also, instead of a National Registry, we received a Data Base for $120,171 which is merely a compilation of names of diagnosed IC patients.

The decision to divert IC budgeted funds into other urological areas was made by the NIDDK Central Advisory Council, Subcommittee on Urology, which is comprised of 1 lawyer and 5 doctors, 4 of whom work in the area of kidney disease. The difference in review scores between the projects that received our money and the IC proposals that were passed over was insignificant, very much like the difference between an A and an A+. The decision of the NIDDK Council has had a devastating effect on the IC research community as well as on patients. Even urologists in private practice here in San Diego have heard the news that the RFA on interstitial cystitis was nothing but a hoax. It is now highly unlikely that any researcher will ever again take an RFA on IC seriously.

In summary, the victims of interstitial cystitis appeal to you for justice. We, the women with urological diseases are the forgotten majority. We appeal to you for a specific IC earmark in the amount of 4 million dollars to bring interstitial cystitis up to par with other urological diseases. It is our hope for the future that all disease victims receive a pro-rata share of our research tax funds. Only you can make it happen. Thank you.

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## STATEMENT OF BOSTON CHILDREN'S HOSPITAL

When kidney and genitourinary (GU) diseases affect a child, they impose large medical, financial and social burdens. Although great progress has occurred during the past two decades to improve the clinical management of these diseases, research focused on their fundamental basis which would ultimately permit complete correction or prevention has lagged far behind.

The kidney and GU diseases affecting children are quite diverse. They are frequently congenital, or have a genetic basis, and are often unfamiliar to medical and surgical subspecialists dealing primarily with adult patients. A recent publication listed 288 childhood disease syndromes which had kidney involvement (Pediatric Nephrology, Williams and Wilkins, 1987, pp 384-404). These kidney diseases are frequently severe, debilitating and life threatening. The care of children with complete and chronic kidney failure demonstrates the severity and cost of these problems both in terms of human suffering and expenditure of health care resources. Each year in the U.S.A., approximately 1,000 children develop end stage renal disease and must be treated with chronic dialysis or renal transplantation. As a result of their renal failure, these children suffer from a variety of serious multiple organ system disorders. One year of chronic dialysis usually costs about $50,000 whereas the first year of care after renal transplantation can cost upwards of $100,000. Thus, the annual cost of the care of only one of these children is equivalent to the support of a typical basic science research project funded by the NIH.

Other kidney and GU diseases that are less severe and debilitating are far more prevalent. Routine fetal ultrasound examinations detect congenital diseases of the urinary tract in 1% of all pregnancies and the affected children manifest a variety of medical problems requiring surgery, medication, and long-term medical follow-up. Five percent of all girls have urinary tract infections and 25% of these children possess an anatomical GU abnormality. If these anatomical or functional problems are not corrected, they often initiate a scarring process culminating in chronic renal failure.

The care of children with kidney and GU diseases has been improved immeasurably by the recognition and development of the subspecialities of pediatric nephrology and urology. Approximately 20 years ago the American Society of Pediatric Nephrology was founded. Pediatric nephrologists in the ensuing years have made unique and important contributions to the understanding of kidney function and development, the pathophysiology of inherited and immunologic renal disorders and the application of the techniques of renal replacement therapy to increasingly smaller and younger patients. In a similar manner, pediatric urology has evolved and addressed the earlier identification and improved treatment of a broad range of congenital diseases of the GU system. Both the Society of Pediatric Urology and the Urology Section of the American Academy of Pediatrics have been organized in response to the growing number of subspecialists in this field.

Although the efforts of pediatric nephrologists and urologists have resulted in great progress in the care of kidney and GU diseases, the emphasis of this past work understandably has been in the treatment rather than research directed at the basic underlying disease mechanisms. Basic research efforts to uncover the mechanisms of these diseases that will, in turn, allow steps to be taken to completely correct or prevent them should be enlarged and increased. The large clinical demands on many pediatric nephrology and urology programs have taken precedence however, and limited expansion of research efforts. Thus, the subspecialties of pediatric nephrology and urology are presently at a critical crossroads.

To address this situation, the American Society of Pediatric Nephrology recently published a position paper on the current status and future needs of pediatric nephrology. Their principal conclusion is that there are very few pediatric nephrology programs possessing the "critical mass" of faculty to provide both sufficient patient care and teaching commitment while simultaneously undertaking basic research on pediatric renal disorders. Similar circumstances exist in pediatric urology. The number of new investigator-initiated funded research projects has dramatically declined due to long term NIH commitments. In this setting, pediatric nephrologists and urologists, many of whom have clinical burdens as well as their research commitments, have been placed in a competitively disadvantageous position.

To improve this situation, the American Society of Pediatric Nephrology position paper recommended the creation of pediatric nephrology centers and the increased support for research relevant to pediatric nephrology. The NIDDK of the NIH has placed the formation and development of Centers of Excellence for the Study of Kidney and Urologic Diseases of Children in its highest category of priorities. The central elements of these centers would include:

1. The centers would be created at a single institution or from a small number of closely collaborating institutions containing a critical mass of faculty engaged in developing a new generation of investigators who will further the progress in pediatric nephrology and urology research.
2. Research conducted in the centers should have high relevance to the fundamental issues of pediatric nephrology and urology. These subjects could include: the molecular development of the kidney and GU tract, basic aspects of cell function such as cell ion and solute transport and volume regulation, molecular genetic investigation of inherited renal and GU disorders, the basic pathophysiology and treatment of growth failure in children with chronic renal disorders and mechanisms of congenital renal and bladder damage in neonates, infants and children.
3. The centers should exist in institutions with an active and productive pediatric research program to facilitate interdisciplinary collaboration with other investigators including those in divisions of genetics, hematology, endocrinology, molecular biology, immunology, physiology and developmental biology.
4. The centers should have productive programs in both basic and clinical research, including an active institutional Clinical Research Center.

Despite widespread recognition of the genuine need for such Centers of Excellence, current NIH and NIDDK funding problems have virtually precluded their development. Therefore, it is unlikely that these centers can be developed without new appropriations for the NIDDK budgets.

In Conclusion:

We propose that there be new appropriations of two million dollars for the NIDDK to use for the development of independent Centers of Excellence for the Study of Kidney and Genitourinary Diseases of Children which will be dedicated to research into the fundamental basis of these diseases.

# STATEMENT OF THE RENAL PHYSICIANS ASSOCIATION

We are pleased to have this opportunity to express our support for increased funding for biomedical research through the National Institutes of Health, (NIH) and the National Institute of Diabetes, Digestive, and Kidney Diseases (NIDDKD). The Renal Physicians Association, (RPA) is a professional organization of nephrologists whose goals are to insure optimal care under the highest standards of medical practice for patients with renal disease and related disorders, to act as a national representative for physicians engaged in the study and management of patients with renal disease and related disorders, and to serve as a major resource for the development of national health policy concerning renal disease.

RPA joins with approximately two hundred other professional and voluntary health organizations in support of funding of $9.2 billion for NIH in fiscal year 1991. The Administration's budget request of $7.9 billion does not provide sufficient funds to meet scientific opportunities currently available: While NIH projects that a 5.9 percent increase in funding would be needed just to maintain our current level of effort, the Administration's proposal (representing only a 4.7 percent increase) falls short of even that mark by nearly $400 million. Funding of $9.2 billion for NIH in fy 91 would allow approximately 30 percent of approved competing research grants to be funded, NIH-wide. Most importantly, it would restore full funding for research project grants and centers, which have been subjected to significant "built-in" cuts in their dollar levels over the last several years, resulting in an inability to properly conduct research.

RPA also advocates an increase in funding for the national Institute of Diabetes and Digestive and Kidney Diseases to at least $736 million in fy 91. Components of this request include the following:

- An additional $5 million to expand the number of Career Development Awards and to adjust the stipend level in each year of training.

- An additional $8 million to increase the funding level of FIRST Awards ensuring sufficient funds to develop independent investigators.

- Additional funds to increase the funding level for R01's to at least the 30th percentile in fy 91.

- An additional $500,000 to increase the number and the stipend levels of Senior Fellowship Awards.

- Additional funding to add additional training positions for pediatric nephrology research to the existing pool of adult and pediatric Institutional Training Grants in fy 91, and for each of the next 5 years.

- An additional $210,000 to add six additional Individual Research Fellowships in pediatric nephrology and pediatric urology.

- Funding to support the issuance of RFA's in special areas of concern requiring further basic and/or clinical research.

- Increased funding to enable the Kidney and Urology program to expand studies on the effects of diabetes on the kidney and on the role of hypertension and its regulation in the progression of diabetic renal disease.

- Additional funding to increase the number of George M. O'Brien Kidney and Urological Research Centers in fy 91.

- An additional $20 million to support additional clinical trials and clinical research in nephrology.

These elements are consistent with the recommendations of the National Kidney and Urologic Diseases Advisory Board in its 1990 Long Range Plan, which was recently presented to the Secretary, HHS and to Congress.

## Kidney Disease Research

Kidney diseases and disorders are among the nation's most critical public health problems. The Federal Government now spends over $3 billion each year on treating end-stage renal disease, including costs of maintenance dialysis in a growing population exceeding 150,000 patients. High priority areas of research to combat kidney disease include: studies of the effects of hormones and diuretics on metabolism of the kidney; the effects of drugs and toxins; the immune system's role in the development of immune renal injury; mechanisms leading to chronic renal disease, including kidney disease of diabetes mellitus and polycystic kidney disease; and therapeutic interventions for end-stage renal disease.

A major research initiative of the Institute is in kidney disease of diabetes mellitus (KDDM), which is the leading cause of end-stage renal disease (ESRD) in the United States. Diabetic patients account for an increasing share of the total ESRD population. The number of patients with end-stage renal disease due to KDDM has risen steadily over the last decade to nearly 30 percent of new patients entering the ESRD Medicare Program. The 5-year survival of patients with KDDM who are receiving dialysis is less than one-half that of dialysis patients without diabetes mellitus. More reliable measurements of kidney function must be developed for clinical assessment of KDDM patients. Without such methods, long-term studies of treatment alternatives and epidemiologic factors cannot be carried out effectively. Last year, the appropriations committees targeted funding for KDDM. RPA strongly supports continued emphasis on improving methods of kidney function assessment in connection with the KDDM initiative.

## U.S. Renal Data System

In 1988, the NIDDK established the United States Renal Data System (USRDS) as part of an interagency agreement with the Health Care Financing Administration. The goals of this newly-established data system are: to create a consolidated renal disease data system to describe and analyze trends; to report regularly on incidence, prevalence, and mortality; to identify modalities of treatment best suited to various types of patients; and to undertake focused investigations of issues currently unaddressed. RPA has been integrally involved in efforts to ensure that the registry functions so that scientific information (supported by the NIDDK) and data from cost studies and quality assessment issues (supported by HCFA) are fully integrated. Only in this way will we be able to generate complete analyses which are needed as we work to improve management and quality of ESRD treatment programs. To this end, RPA supports efforts to see that the recently-chartered ESRD Data advisory committee is set to begin substantive action in a timely manner.

## Conclusion

In the current fiscal year the NIDDKD will be able to support only about 22% of approved research grants. Given the enormous opportunities available in kidney disease research and the high economic toll kidney disease takes on our national economy, we believe that this situation must be addressed. The long range plan of the National Kidney and Urologic Diseases Advisory Board recognizes the large body of basic science information which is available for application to kidney diseases if sufficient financial resources are made available. We urge the committee to take all reasonable efforts to provide an increase over the President's request for biomedical research and specifically for the NIDDKD. RPA would be happy to provide you with more specific information relating to kidney disease research and research funding matters.

## STATEMENT OF THE NATIONAL FOUNDATION FOR ILEITIS AND COLITIS

For over twenty years, the National Foundation for Ileitis and Colitis has fulfilled its civic responsibility and its scientific mission by presenting testimony to the Senate and House health appropriations subcommittees.

We have shared with you issues, concerns, and opportunities to aid the federal government fulfill its mandate to help diminish or eradicate two of our nation's chronic and devastating diseases--Crohn's disease (ileitis) and ulcerative colitis. (These diseases are also referred to as inflammatory bowel diseases or IBD. A fact sheet about IBD is enclosed.)

There have been many years when we have applauded the federal effort in this regard. Last year, with specific language in the Senate Appropriations Bill, the IBD research program of the Digestive Diseases Division of the NIDDK was strengthened.

This year, we return to thank you for that heightened federal interest and to announce a dramatic new course of IBD research directions and opportunities that will surely maximize the effectiveness of government and private sector resources:
**"Challenges in IBD Research: Agenda for the 1990s."**

A panel of outstanding experts, many of whom were or are currently supported by NFIC and/or NIH funds, was convened by the NFIC in Indian Wells, California, November 1-4, 1989, to discuss and prioritize needs in nine areas of IBD research. Dr. Stephan Targan of UCLA, NFIC's National Scientific Advisory Committee Chairman, led this monumental effort by selecting the nine members of the panel who represented nine specific but interrelated disciplines. Before the November meeting, each of the panel members had conferred with several colleagues in his subspecialty, so that the final endeavor was the consensus of over forty recognized authorities in clinical and basic research disciplines from the United States and Canada. (A list of these researchers and their affiliations is enclosed.)

The document entitled "Challenges in IBD Research: Agenda for the 1990s" resulted from the three intensive days of discussion in Indian Wells. It outlines in considerable detail the future direction of IBD research for the next five to ten years.

It is our understanding that the NIDDK and other NIH institutes, which direct some funds to IBD-related projects, intend to endorse the contents of the document, our blueprint for progress in IBD research.

The excellent NIH and NFIC research partnership, about which NFIC has testified almost every year since its founding in 1967, has served our IBD public well. In the last few years, some sixteen out of twenty NIH researchers were initially funded by the NFIC. But now, with the advent of new technologies and insights as expressed in the "Challenges..." document in the fields of genetics, immunology, and cell biology, this partnership will be tested as never before.

The challenges and opportunities are now here. They are ready to be refined and to direct research down critical new pathways. New scientific pathways and proactive determination by the NIDDK in directing cystic fibrosis and diabetes research dramatically accelerated the research advances in those diseases. The impressive manner in which the NIDDK and the Cystic Fibrosis Foundation, and the American Diabetes Association and the Juvenile Diabetes Foundation, worked their research partnerships is to be applauded and emulated.

In this regard, the NFIC has selected four of the many recommendations advanced in the "Challenges..." document as those most suitable for the NIH and that require NIH involvement. Support of these four areas could very possibly lead to a quantum leap in IBD research.

The four priorities, in rank order, which we believe merit the most serious attention from the NIH, are as follows:

1) **TISSUE BANKS.** Detailed basic science investigations are necessary to identify the genetic basis of IBD suggested by the genetic and epidemiological data we already have. The most important strategy for these investigations is the establishment of a comprehensive cell line bank with information correlated to a DNA and serum bank. The project could be initiated immediately. The goal would be to establish permanent cell lines in culture from 1500 to 2000 well-characterized patients with IBD, their family members, and appropriate disease-related controls. High priority would be placed on establishing cell lines from families with multiple affected cases. A consortium of institutions in New York, Chicago, Iowa City, and Los Angeles is already geared up to proceed with this project. With potentially 10,000 samples to be collected, a staggering amount of work is needed to categorize and catalogue such samples, distribute them to investigators, and correlate data. A second strategy is to explore specific candidate genes by association and linkage studies, making use of the Human Genome Project that is mapping all human genes. The purpose of this initiative is to identify the specific genes that predispose to IBD.

We recommend that $500,000 be made available through RFAs for the next fiscal year to move ahead with this project. Among the necessities are technical support, computer software, freezing equipment, and other resources.

**2) EPITHELIAL CELL GROWTH AND FUNCTION.** The epithelial cell has been advanced as a major player in the pathogenesis of IBD, but the normal mechanisms and regulation of epithelial cells must be better defined. Progress in understanding the role of the epithelium is partially dependent on the development of long-term intestinal epithelial culture systems. Among other advantages, these will help establish the functional significance of cell surface antigens on epithelial cells, which requires gathering a significant amount of preliminary data. In short, the function of normal epithelial cells must be clarified, and the altered function in IBD must be documented.

We recommend that **$500,000** be made available through RFAs for the next fiscal year to move ahead with this project.

**3) SEED MONEY FOR NEW BASIC SCIENCE PROJECTS.** Basic science investigators, with different perspectives relevant to disease pathogenesis and response to treatment, should be encouraged to enter the arena of IBD research. Without doubt, to make progress we need to increase available manpower to do research. Young scientists have to be recruited to make IBD their focus, and established investigators, who may be focusing on other diseases, need to be encouraged to apply their expertise and specialties to IBD. They need to be exposed to the field, and funds must be available to support their investigations. As more and more basic science investigators become aware of the need to look at IBD, the urgency to form liaisons between their laboratories and IBD experts is apparent. Seed money to initiate these interactions is necessary.

We recommend that **$400,000** be made available as seed money grants to sites that are actively involved in IBD research that can additionally attract new basic science people into the field.

This would be an ideal way of fostering existing research and nurturing new ideas and expertise.

**4) SUPPLEMENTATION OF RO1 GRANTS.** The NIH has supported IBD research in the form of RO1 grants and IBD Centers, and will continue to support them in this fiscal year. A considerable amount of significant work has been produced through these funding mechanisms. In the face of probable cutbacks in the NIH budget, such as occurred this year, it is important that adequate funding be assured for the continuation of existing programs and projects.

We recommend that **$600,000** be made available as supplementary funds for those RO1 grants that would suffer cutbacks as a result of NIH budget restrictions.

These important projects amount collectively to **$2 million.** With some 2 million IBD sufferers in the United States and 30,000 new cases diagnosed annually, we believe this investment opportunity provides a sound, critically directed, and coordinated approach to help solve a significant health problem.

The NFIC is committed to increase its $2 million research budget to $10 million to help meet the needs of the "Challenges..." project. The pharmaceutical firms that are developing drugs to help in the treatment of IBD have manifested their interest in advancing IBD research in concrete and significant financial ways by contributing to the NFIC's Corporate Circle.

**With the NIH, the NFIC, and industry directing their research in collaboration, we believe that a quantum leap in knowledge about the possible cause and cure for these diseases will occur before the end of the 1990s. With your help and support, the NIH will be able to do its share to assure that optimistic future.**

The NFIC supports NIDDK's professional judgment budget of $808 million for research expenditures in FY 1991.

Thank you for affording us this opportunity to offer testimony regarding this IBD agenda for the 1990s.

## FACTS ABOUT INFLAMMATORY BOWEL DISEASE (IBD)

* Crohn's disease (ileitis) and ulcerative colitis (collectively known as inflammatory bowel disease or IBD because their symptoms and complications are similar) are chronic inflammatory diseases of the small and large intestines.

* It is estimated that two million Americans suffer from IBD, with 30,000 new cases diagnosed in the U.S. each year. New cases per day average 82, or 3.5 an hour.

* Anyone can get IBD, but young adults between the ages of 20 and 40 are most susceptible. (10 percent or 200,000 of those afflicted are youngsters under the age of 18.)

## SYMPTOMS

* Symptoms range from mild to severe and life-threatening and include any or all of the following:
- persistent diarrhea
- abdominal pain or cramps
- blood passing through the rectum
- fever and weight loss
- skin or eye irritations
- delayed growth and retarded sexual maturation in children

* 20-25 percent of patients have another family member with IBD, although a specific genetic pattern has not been identified.

* Both the cause and the cure of IBD are unknown.

## TREATMENT

* Medications currently available alleviate inflammation and reduce symptoms but do not provide a cure. The principal drugs used to treat both Crohn's disease and ulcerative colitis are sulfasalazine and corticosteroids.

* A number of new medications, derivatives of corticosteroids and sulfasalazine, are currently awaiting FDA approval. One such drug, Rowasa™, was released in January, 1988.

* Immuno-suppressive agents, such as azathioprine (Imuran) and 6-mercaptopurine (6-MP) are other medications used to treat IBD, especially in persons who do not respond to more standard treatments.

* IBD is an unpredictable illness -- some patients recover after a single attack or are in remission for years; others require frequent hospitalizations and even surgery. Symptoms may vary in nature, frequency and intensity.

* Without proper treatment, symptoms may worsen considerably and complications may occur.

* Colon cancer may be a serious complication of long-term ulcerative colitis involving the whole colon, even in a patient who is in remission.

## SURGERY

* Surgery is sometimes recommended when medication can no longer control the symptoms, when there are intestinal obstructions, or when other complications arise.

* An estimated two-thirds to three-quarters of persons with Crohn's disease will have one or more operations in the course of their lifetimes. The surgery for Crohn's disease, however, is not considered a permanent cure, because the disease frequently occurs elsewhere in the gastrointestinal tract. For ulcerative colitis, surgical removal of the entire colon and rectum (colectomy) is a permanent cure. About 15-20 percent of ulcerative colitis patients have to undergo colectomy eventually.

## EMOTIONAL FACTORS

* IBD is not a psychosomatic illness -- there is no evidence to suggest that emotions play a causative role. IBD flare-ups may occur, however, during times of emotional or physical stress.

## DIET

* There is no link between eating certain kinds of foods and IBD, but dietary modifications, especially during severe flare-ups, can help reduce disease symptoms and replace lost nutrients.

## EFFECTS ON THE PERSON WITH IBD

* The economic and social burden on patients and their families can be enormous. Children and adults must interrupt school and work for repeated hospital stays, and medical and disability insurance often are unavailable.

# CHALLENGES IN INFLAMMATORY BOWEL DISEASE RESEARCH: AGENDA FOR THE 1990s

## CONTRIBUTING SCIENTISTS

STEPHAN R. TARGAN, MD, Chairman
UCLA Medical Center
Los Angeles, CA

### BIOCHEMISTRY/MOLECULAR BIOLOGY

Chairman: Daniel Podolsky, MD; Massachusetts General Hospital, Boston, MA
Panel: Jeff Gordon, MD; Washington Univ. School of Medicine, St. Louis, MO
Richard Grand, MD; Tufts New England Medical Center, Boston, MA
Young S. Kim, MD; Univ. of California Medical Center, San Francisco, CA

### CELL BIOLOGY

Chairman: Marian R. Neutra, PhD; Harvard Medical School, Boston, MA
Panel: James L. Madara, MD; Brigham and Women's Hospital, Boston, MA
Andrea Quaroni, PhD; Cornell University, Ithaca, NY
Richard D. Rodewald, PhD, University of Virginia, Charlottesville, VA

### CLINICAL STUDIES

Chairman: Stephen B. Hanauer, MD; University of Chicago, Chicago, IL

Panel: Theodore M. Bayless, MD; The Johns Hopkins University, Baltimore, MD
Fred Daum, MD; North Shore University Hospital, Manhasset, NY
David B. Sachar, MD; Mount Sinai Medical Center, New York, NY
Rodger C. Haggitt, MD; University of Washington, Seattle, WA

## DRUG DEVELOPMENT

Chairman: William F. Stenson, MD;
Washington University School of Medicine, St. Louis, MO

## GENETICS

Chairman: Jerome I. Rotter, MD; UCLA School of Medicine, Los Angeles, CA
Panel: Randall Burt, MD; University of Utah, Salt Lake City, UT
Richard King, MD; University of Minnesota, Minneapolis, MN
Edward H. Leiter, PhD; Jackson Laboratories, Bar Harbor, ME

## IMMUNOLOGY

Chairman: Charles O. Elson, III, MD; Univ. of Alabama, Birmingham, AL
Panel: John Bienenstock, MD; McMaster University, Hamilton, Ontario
William Koopman, MD; Univ. of Alabama, Birmingham, AL
Lloyd Mayer, MD; Mount Sinai Medical Center, New York, NY
Warren Strober, MD; National Institutes of Allergy
and Infectious Diseases
Bethesda, MD

## INFLAMMATORY MEDIATORS

Chairman: William F. Stenson, MD; Washington University, St. Louis, MO
Panel: Claudio Fiocchi, MD; Cleveland Clinic Foundation, Cleveland, OH
Matthew B. Grisham, PhD; Louisiana State Univ. Med. Ctr., Shreveport, LA
Joel Weinstock, MD; University of Iowa, Iowa City, IA

## INTESTINAL MICROBIOLOGY

Chairman: R. Balfour Sartor, MD; Univ. of North Carolina, Chapel Hill, NC
Panel: Martin Blaser, MD; Rockefeller University, New York, NY
Vinton S. Chadwick, MD; Wellcome Medical Research Inst.
Dunedin, New Zealand
W. Allan Walker, MD; Massachusetts General Hospital, Boston, MA
Jacqueline Wolf, MD; Brigham and Women's Hospital, Boston, MA

## PHYSIOLOGY

Chairman: William J. Snape, Jr., MD; Harbor-UCLA Medical Center, Torrance, CA
Panel: Helen J. Cooke, MD; Ohio State University, Columbus, OH
John W. Dobbins, MD; Yale University School of Medicine, New Haven, CT
James A. McRoberts, PhD; Harbor-UCLA Medical Center, Torrance, CA
Sidney F. Phillips, MD; Mayo Clinic, Rochester, MN

AD HOC MEMBER: Richard P. MacDermott, MD
Hospital of the University of Pennsylvania
Philadelphia, PA

# STATEMENT OF THE NATIONAL KIDNEY AND UROLOGIC DISEASES ADVISORY BOARD

I am Stuart A. Kleit, D.D.S., M.D., associate dean for clinical affairs at the Indiana University School of Medicine and chairman of the National Kidney and Urologic Diseases Advisory Board.

The Board, as directed by Congress and the Secretary of Health and Human Services, has developed the first national long-range plan to combat kidney and urologic diseases. In this effort, it was aided by more than 1,000 medical professionals, patients, and members of the public. Now completed, the plan provides specific recommendations for the utilization and organization of national resources to address the needs of Americans suffering from kidney and urologic diseases. The plan and the executive summary have been provided to members and staff of your subcommittee.

## The Burden of Kidney and Urologic Diseases

The data we obtained on the incidence, prevalence, and cost of kidney and urologic diseases revealed that there are hundreds of kidney and urologic diseases that today affect approximately 13 million Americans of all ages--from the newborn to the elderly. Urinary incontinence and urinary tract infections are major health problems in older persons, as is prostate cancer --the second leading cause of cancer deaths in American men. Benign prostatic hyperplasia--the enlargement of the prostate gland as men age--can eventually destroy normal bladder function, resulting in severe infections of the urinary tract and, ultimately, permanent kidney failure.

Minority populations also suffer a disproportionate share of kidney and urologic diseases. For example, black Americans die from prostate cancer at twice the rate and are affected by end-stage renal disease at four times the rate of white Americans.

The financial burden of kidney and urologic diseases is staggering--an estimated $50 billion, or more than 8 percent of the total spent on all diseases. These expenses are borne by patients, their families, third party payers, and Federal and state governments. The costly treatments for end-stage renal disease are funded primarily by Medicare, whose expenditures for the care of 157,944 patients in 1987 exceeded $3.4 billion. In 1985, hospitalizations and physician visits for prostate diseases cost nearly $3 billion, most of it funded by Medicare. In addition, urinary incontinence has been estimated to cost Americans anywhere from $1.8 billion to $8 billion annually. As the population of the United States expands, particularly the 65-and-older segment and minority groups, the costs of kidney and urologic diseases are projected to increase dramatically.

Strengthening the Research Effort

The National Institutes of Health (NIH) has been the guiding influence responsible for many research breakthroughs in the struggle against kidney and urologic diseases. Nevertheless, in 1988 NIH allocated only an estimated $188 million to research and development in this area--a very small fraction, 2 percent, of its budget. This is distressing in light of the significant human and economic costs of these diseases.

In 1987, with authorization and appropriations from Congress, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) established six George M. O'Brien Kidney and Urological Research Centers to conduct basic and clinical research into the cause, diagnosis, early detection, prevention, and treatment of kidney and urologic diseases. As originally envisioned, each of the O'Brien research centers was to be supported for 5 years at a level of $1 million per center per year. However, fiscal constraints resulted in a first-year appropriation of only $4 million to support the centers. Therefore, the Board recommends that:

- Congress appropriate an additional $15 million per year to NIDDK to increase the number of George M. O'Brien Kidney and Urological Research Centers from 6 to 18 with full funding of all centers. In addition, funding for the centers must be expanded to include research training.

The centers concept also has a critical role in unraveling the problems of kidney and genitourinary cancers. The Board is concerned that, despite current National Cancer Institute (NCI) involvement in urologic cancer research, the Institute's total support directed to this area in fiscal year 1988 amounted to only 2.3 percent of its budget. Based on the significant and growing public health impact of these cancers, and prostate cancer in particular, the Board recommends that:

- **Congress appropriate an additional $10 million per year to NCI to establish six centers to study cancers of the prostate, bladder, kidney, and testis.**

The Board has determined that the fields of nephrology and urology increasingly lack the ability to ensure an adequate supply of committed, well-trained scientists. Funding for nephrology and urology research training programs, based primarily within NIDDK, has not kept pace with the need. The situation is particularly deplorable in pediatric urology and pediatric nephrology where NIH-supported research training is virtually nonexistent. The Board is also extremely concerned about the minimal funding levels of investigator-initiated research project grants. These grants encourage and support meritorious research efforts, many of which yield major scientific breakthroughs. In fiscal year 1989, no more than 20 percent of meritorious R01 applications were funded in both nephrology and urology and in fiscal year 1990 the situation is expected to be worse.

After thoroughly reviewing current and past research and research training activities, the Board recommends:

- **Equitable funding of approved Research Project Grant (R01) applications between and within the divisions of NIDDK occur during fiscal year 1991. Furthermore, that Congress appropriate an additional $46 million per year to NIDDK to increase the funding level for R01's focused on kidney and urologic diseases to the 50th percentile within 5 years.**
- **Congress appropriate an additional $8 million per year so that NIDDK can substantially and steadily increase funding for Institutional Training Grants and Individual Research Fellowships in kidney and urologic diseases.**
- **Congress appropriate an additional $800,000 per year for NIDDK to add a total of four training positions for pediatric nephrology and pediatric urology research to the existing pool of adult and pediatric Institutional Training Grants for each of the next 5 years. Also, that Congress appropriate an additional $210,000 per year to NIDDK to add six additional Individual Research Fellowships in pediatric nephrology and pediatric urology.**

- **Congress appropriate an additional $5 million per year to NIDDK to expand the number of Career Development Awards and inflation-adjust the stipend level in each of the 5 years of urology and nephrology training.**

Maximizing the Yield on our Investments in Research

Public health education is one mechanism that facilitates the transfer of frequent health advancements and treatments from the laboratory to individuals in need. A comprehensive plan for public education would have the potential to save more lives and reduce the pain and expense of preventable diseases. The Centers for Disease Control possesses the expertise required to develop public health programs in kidney and urologic diseases and to plan for their implementation and evaluation.

An NIDDK health education program could review the established health education programs in the private and public sectors and help establish priorities to improve activities in areas not currently addressed by national programs. New health education programs could then be designed for those diseases that have substantial societal impact with the potential for amelioration by health education intervention. Therefore, the Board recommends that:

- **Congress authorize 18 personnel positions and appropriate an additional $10 million per year to the Centers for Disease Control to establish a comprehensive public health program to address problems in kidney and urologic diseases.**
- **Congress authorize 10 personnel positions and appropriate an additional $4 million per year to NIDDK to establish a national kidney and urologic diseases education program to address prevention and early detection through health education in specific disease areas.**

The Board was appalled to learn that school health education programs distributed by the Centers for Disease Control for use in grades 1-12 contained no information on the kidney or urinary tract. To overcome this problem and ensure that this country's youth at least has some understanding of the kidney and urologic tract, the Board recommends:

- **Congress authorize two personnel positions and appropriate an additional $1 million per year to the Centers for Disease Control to develop**

**appropriate age-specific information on kidney and urologic disease for use in school health education curriculums.**

I wish to close by thanking the subcommittee for its past and continuing support of biomedical research into the prevention and treatment of kidney and urologic diseases; for establishing this Board; and for encouraging the development of a national plan that endeavors to reduce and, ultimately, to eliminate the burden these diseases impose on the citizens of our Nation.

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## STATEMENT OF THE AMERICAN SOCIETY OF NEPHROLOGY

Mr. Chairman and distinguished Members of the Subcommittee, thank you for the opportunity to place the statement of the American Society of Nephrology (ASN) into the record for your Subcommittee's deliberation. The ASN has 4,500 members across the country who are using basic and applied research efforts to improve the treatment of Americans suffering from kidney and related diseases.

On behalf of our members, I would like to thank you for the long standing support that this Subcommittee and the Congress has shown for medical research. The scientific community is well aware that the legislative branch has been our champion in assuring that funding is at hand to pursue the many opportunities available in medical research.

Before I briefly highlight our research efforts and needs, I would like to put the impact of kidney diseases into perspective.

- Kidney and urologic diseases affect over 13 million Americans, with minorities suffering a disproportionate incidence.
- In 1987, over a quarter of a million people died from kidney and urologic disorders.
- Over $50 billion, or 8% of the total cost of all health care costs, is spent on the management of kidney and urologic disorders each year.

These statistics clearly indicate a need to re-examine our research funding priorities. Innumerable research opportunities exist that might allow us to alter these grim statistics, and modify our high rate of renal and urologic disease incidence and morbidity. We look to the Members of this Subcommittee for your assistance in realizing these research opportunities.

I will address the FY 1991 President's Budget Request for the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK) as it relates to three important aspects of research: funding for basic research and training, research opportunities, and the use of animals in research.

### Funding for Research and Training

In the FY 1991 President's Budget Request for the NIDDK is woefully inadequate to address the major advances resulting from a decade of investment in molecular biology. The NIDDK received an increase of $24 million, for a total recommendation of $605 million. That level of funding will bring about the following results at NIDDK:

- a decrease in noncompeting grants from 1607 to 1534 with an 11% downward negotiation -- or cut. This is on top of a 12% downward negotiation in 1990.
- 30% downward negotiation for research centers in order to maintain a constant number of 40 centers;
- level funding of research training;
- level funding of research and development contracts;
- 4.6% increase in intramural research;
- a 3.2% increase in award rate (from 22.4% to 25.6%), because of the decrease in noncompeting grants.

**American Society of Nephrology Funding Recommendations**

The renal research community views the above outcomes as unacceptable at best, and in most areas absolutely disastrous. ASN supports the funding recommendations of the Ad Hoc Group for Medical Research, which would provide $9.2 billion for programs at the NIH. This is the minimum required to stabilize research efforts, and this stabilization is crucial to the extramural research community to ensure continued productivity of federally supported initiatives.

However, we need more than minimum funding to pursue the critical research opportunities available today that would hasten our ability to reduce the incidence, suffering, and costs of renal and urologic disease. We urge Congress to fund the NIDDK at $770,700,000 for FY 1991, a $165,351,000 increase over the President's 1991 Budget recommendation. Funding at this level would result in the following:

- Full funding of awarded competing and noncompeting grants;
- An increase of 15 new centers, bringing the total to 55, and full funding of all existing centers;
- Research training increases of 10% over the current level. (This would provide for a total of 1,000 research trainees, up from 895);
- An increase in Research Career Awards from 178 to 200;
- An additional $7 million for clinical trials;
- Maintenance of the intramural research program at 10% of the total institute budget; and
- An award rate of 45% of approved competing grants.

Without this level of support from Congress, research progress in kidney disease is threatened. Over 16 initiatives recommended in the Division of Kidney, Urologic, and Hematologic Diseases are likely to go unfunded given the current budget proposal. These initiatives include: kidney disease associated with diabetes mellitus; studies of inherited, acquired or induced polycystic kidney disease; and fundamental research and clinical studies in pediatric nephrology. Further, there is a pressing need to address the disproportionate incidence of kidney disease in blacks. Such an initiative should include a comprehensive action plan for epidemiological, basic, and clinical research to address all aspects of renal disease in this population.

**Research Opportunities**

Significant progress has occurred in nephrology, despite the fact that we are relative newcomers to the research effort. Four decades ago, few nephrologists existed. Twenty years later, the "best and the brightest" young medical scientists were choosing nephrology for their field of study. Nephrology has progressed to the point where additional Federal research funds are both well-justified and imperative.

Many exciting opportunities await us. The private sector and Government must work together to formulate strategies to shape future progress toward the conquest of kidney and other related diseases. This can be done by:

* Promoting basic and applied research efforts that will serve as the basis for new preventative, diagnostic, and therapeutic strategies;
* Improving access to medical care appropriate to the diversity of kidney diseases and the populations they strike; and
* Improving public, patient, and professional awareness of the opportunities for prevention, early detection, treatment, and rehabilitation.

Kidney and urologic diseases are on the rise. The cost of treating these diseases is high and continues to grow. Last year, the Health Care Financing Administration (HCFA) alone spent $3 billion just for treatment of End Stage Renal Disease (ESRD). Millions more are spent by individuals and private insurers, and indirect costs, such as lost productivity, are estimated to be in the billions.

Research investigators are at the core of our ability to solve the problems of kidney and urologic disease, and more research is desperately needed. Money spent on research funding now is an investment in tomorrow, and it represents an opportunity to save millions of future dollars that will otherwise continue to be expended for costly treatments.

**Use of Animals in Research**

I would also like to emphasize the significance of the use of animals in biomedical research. We are committed to the support and encouragement of biomedical research so that new information may be discovered that will lead to more effective treatment, diagnosis, and, eventually, to cure and prevention of all forms of kidney diseases. To accomplish the goals of the American Society of Nephrology, we recognize the essential role of animals in biomedical research. We further believe that animals must be treated humanely and that the liberty to use animals must not be abused.

This Subcommittee is well aware of the passions surrounding this issue. But, scientists and clinicians must have the strong support of Congress to ensure the advancement of biomedical research. Such research will surely yield new knowledge and treatments that can positively affect the incidence and progress of kidney and related diseases.

**Summary**

In conclusion, the American Society of Nephrology asks that you support funding of the NIDDK at $770 million in FY 1991. We believe that now is the time to make an investment in this field, to build on the past contributions of scientists and clinicians, and to capitalize on the past investments of the Federal Government and the private sector.

Mr. Chairman and members of the Committee, thank you for the opportunity to present testimony on behalf of the American Society of Nephrology.

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## STATEMENT OF THE AMERICAN DIABETES ASSOCIATION

The American Diabetes Association (ADA) is the nation's largest voluntary health agency serving the health-care and medical research interests of nearly 12 million individuals with diabetes. The ADA is comprised of 58 state affiliate associations, 800 local chapters, and over 220,000 lay and professional members and is pleased to have the opportunity to submit testimony on behalf of the National Institutes of Health and the Centers for Disease Control.

### Where We Have Come: Advances in Diabetes Treatment

1921 marks the year insulin was discovered and thus, a whole new era for the treatment of diabetes was ushered in. Insulin has allowed millions of individuals with diabetes -- who previously were fated to die over a short period of time--to live nearly normal lives. Although the discovery of insulin in the 1920s helped prolong the lives of individuals with diabetes, still little was known even into the 1950s about the disease process and about the severe complications from which patients suffer. Through forty years of research at the National Institute of Diabetes, Digestive, and Kidney Diseases (NIDDK), we now know a lot more about the disease. Major advances have been attained in improved diagnosis and clinical management of diabetes. Self-monitoring of blood glucose, pancreas and islet cell transplants, oral medications, understanding the role of obesity in the onset and prevention of diabetes, medications to prevent or forestall complications, sophisticated blood tests to aid in assessing blood glucose levels, laser therapy to prevent diabetes-caused blindness, and new insight into the dietary needs of people with diabetes are just some of the recent advances that are helping many live healthier, longer lives.

New Frontiers: Where We Are Going

Today, we know that diabetes is not just one disease with one cause. There is promising research for new treatments for diabetes, such as a new device which would function as an artificial pancreas. Researchers are now working to develop a reliable implantable automatic glucose sensor that could monitor glucose levels constantly without intervention by the patient, thus rendering an insulin infusion device, more commonly known as an insulin pump, fully automatic. Rapidly expanding capabilities in biotechnology are helping scientists examine the relationship between the occurrence of diabetes and certain genes. There is a major genetic risk factor for diabetes and we know at least one error in DNA that marks this risk. The basic knowledge and the scientific tools now exist to ask and pursue the more specific questions that may unravel the mystery of diabetes.

The Fact: There is Still A Lot To Do

Although progress has been made in diabetes research, we have not come far enough. Serious morbidity and mortality occurs in individuals with the disease. Diabetes is among the leading underlying causes of heart disease, stroke, and kidney disease -- not to mention death. It is the number one cause of new blindness in adults and of non-traumatic foot and leg amputations. Diabetes occurs with disproportionate frequency among minority populations as compared to the general population. Health-care and related costs for diabetes treatment run to $20.4 billion annually and account for nearly 5 percent of total U.S. health-care costs. These figures only reflect the costs of known diabetes; it is estimated that one-half of the nearly 12 million Americans with diabetes do not know they have it.

Biomedical Research and the State of the Nation

The United States has been the leader in biomedical research because of the strong commitment between government and the private sector. However, there is a current disturbing trend of declining funding for research. The logic behind a commitment to increased support of biomedical research is well-founded. There are few Federal investments that can return so much in dividends. Witness the panoply of life-saving advances of modern medicine -- including the discovery of insulin for the treatment of diabetes. This nation cannot afford to be complacent when there is so much potential.

The Time is Now: ADA's Recommendations For NIH and NIDDK

We fully support the recommendation of the over 39 voluntary health agency members of the National Health Council and as supported by Dr. Raub, Acting Director of NIH, before this Subcommittee for a FY 1991 appropriation of $11.679 billion for the NIH as a whole. We strongly believe this recommendation reasonably reflects what the NIH needs to meet the demand of our nation's research agenda. We believe that adopting any other funding level would undermine our country's research infrastructure and further erode this nation's preeminence in biomedical research.

For the NIDDK, we vigorously recommend a FY 1991 appropriation of $808.391 million. This funding proposal addresses some of the most urgent needs of the Institute: full funding of research project grants at a 45% approval rate, full funding of the forty diabetes research centers, an addition of 15 new centers, and funding of 1000 research trainees. By FY 1992, we believe grants should be funded at an approval rate of 50%.

Centers for Disease Control (CDC)

CDC's diabetes program was initiated in 1977 in response to the National Diabetes Advisory Board's (NDAB) 1977 Long-Range Plan to Combat Diabetes. Since that time, CDC has provided financial and technical support to state health departments to focus local expertise on diabetes issues, to initiate surveillance and monitoring activities on diabetes, and to improve access and coverage of known effective preventive interventions, such as patient education and eye disease screening for individuals with diabetes.

The NDAB recommended in the 1987 Long-Range Plan to Combat Diabetes that CDC create a new "translation center" which would translate state-of-the-art diabetes research findings into the practice of medicine. The Division of Diabetes Translation (DDT) is now one of seven major components of the Center for Chronic Disease Prevention and Health Promotion (CCDPHP). The CCDPHP is the newest organizational unit at CDC and its primary missions are the prevention and control of chronic diseases; health promotion in general; and the promotion of infant, child, and maternal health.

The DDT is responsible for national efforts to transfer scientific advances made through diabetes research into actual patient care. The Division's work can be divided into five major program activities: 1) evaluating the feasibility and effectiveness of potential prevention and control strategies; 2) developing clinical and public health guidelines; 3) providing technical consultation and assistance to State and local health agencies; 4) conducting national programs to reduce diabetes-related morbidity; and 5) conducting surveillance of diabetes and its complications.

The NDAB recommended that CDC's $7.2 million budget for diabetes ($5.0 million in state grants and $2.2 million in direct operations) be increased by $14 million to support the new "translation center." In FY 1988, $2.4 million of the $14 million was appropriated to initiate the translation activities. The same amount has been provided for fiscal years 1989 and 1990.

ADA Recommendation: Full funding of the translation center at the CDC requires an additional $11.6 million to bring it to the total of $14 million as recommended by the NDAB. ADA recommends for FY 1991 that an additional $6 million of the recommended $11.6 million be appropriated to support 30 Diabetes Control Programs at $250,000 average award ($3 million) and the translation center epidemiologic studies and community trials ($3 million). By FY 1995, it is anticipated that the final $5.6 million will be provided to DDT, thereby completing the NDAB Long-Range Plan.

We owe much of this country's progress in diabetes research to you, Mr. Chairman, Members of this Subcommittee, and Congress in general for the leadership and foresight you have provided in recognizing the benefits, in human and economic terms, of the Federal investment in medical research. Although the President's FY 1991 budget increases NIH funding. In real dollars, funding for the NIH has in fact declined. We urge you now to make a renewed commitment to the health of our nation by increasing appropriations to NIH.

## NATIONAL EYE INSTITUTE

### STATEMENT OF MORTON F. GOLDBERG, M.D., F.A.C.S.

Mr. Chairman and Members of the Committee: I am Dr. Morton F. Goldberg, President of the Association for Research in Vision and Ophthalmology, President of the Association of University Professors of Ophthalmology, and Director of the Department of Ophthalmology at the Wilmer Ophthalmological Institute, Johns Hopkins University School of Medicine. It is my privilege to testify before this distinguished Committee in support of the Citizens' Budget Proposal for the National Eye Institute for Fiscal Year 1991 under the auspices of Research to Prevent Blindness, the nation's leading voluntary organization in support of eye research.

I am aware of the extraordinary need to control the federal deficit. Congress has many difficult and painful decisions to make in arriving at a national budget that curbs expenditures without jeopardizing essential federal programs and services. The proposal we present is the product of long discussion and final consensus among representatives of the public in consultation with professional organizations most deeply concerned with the problems of vision loss and the control of blinding diseases. All are conscious of the imperative for fiscal restraint -- and that is reflected in a budget total that is less than last year's request. We do believe, however, that in presenting a Citizens' Budget Request, we have an obligation and a duty to define the minimum essential needs of eye research in dealing with the human catastrophe of visual disability.

Eye research is of fundamental importance to all Americans. For the eye is the most vulnerable of human organs. It is attacked by bacteria, by viruses, by fungi, by genetic flaws, by chemical and physical agents, by the body's own tissues and by the very light that makes sight possible. As a result, more than 100 million citizens are afflicted with eye diseases. Persons age 65 and older are especially vulnerable. This age group -- about 12 percent of the population -- represents more than half of the blind population and accounts for nearly one-third of the 34 million visits each year to physicians' offices for medical eye care.

As the baby-boom generation ages, those 40 and over are estimated to increase from 92 million today to 118 million by the year 2000. The Baltimore Eye Study just completed by investigators at Johns Hopkins and funded by the National Eye Institute was conducted to gather accurate and current information on the prevalence of blindness and visual impairment in this older age group. By projecting our findings to the nation as a whole, we estimate that there are more than 3 million Americans 40 years or older so visually impaired they would fail vision requirements for driving in most states. Almost one million are bilaterally blind -- twice as many blind as previously thought.

Much of this loss of sight appears to be related to patients being alarmingly unaware of their potentially-blinding conditions. Over half the individuals with glaucoma in our study, and almost 85 percent of subjects with visual impairment from diabetes, did not know they had these diseases. Yet, treatment is widely available to reduce the likelihood of blindness from these disorders -- thanks to the National

Eye Institute's well-planned multi-center clinical trials. These trials have shown, for example, that timely laser treatment is highly effective in reducing by more than 60 percent the risk of blindness from the retinal complications of diabetes.

There are today 12 million diabetics, and 40 percent of them are estimated to suffer ocular complications of the disease. Eventually, most diabetics develop retinopathy. Improving patient and professional awareness of the importance of early detection and treatment is imperative if we are to reduce unnecessary visual loss from diabetes. A National Eye Health Education Program authorized by Congress is being developed under the direction of the National Eye Institute to fill this crucial need. Prompt treatment of all eligible patients could save one billion dollars over the next twenty years. This savings figure -- from a new and rigorous economic analysis based on years of clinical data collection -- is more than twenty times the combined cost of the NEI-sponsored Diabetic Retinopathy Study and the Early Treatment Diabetic Retinopathy Study which have made such treatment possible.

Although diabetic eye disease is the leading cause of new cases of blindness in Americans aged 20 to 44, it ranks second to macular degeneration as an agent of blindness in those 45 and older. Macular degeneration frequently causes scarring of the highly sensitive central retina used to read and drive. Laser therapy, shown to be effective in NEI-supported clinical trials, now makes it possible to prevent the onset of blindness in 75 percent of selected typical cases. The potential net annual savings are more than $60 million and far exceed the cost of the research. Promising research now in progress could lead to a manifold increase in these savings.

For instance, most patients with macular degeneration are not now candidates for existing therapy. I can report that a new laser treatment approach being developed and tested at The Johns Hopkins Wilmer Eye Institute may possibly prevent or delay significant scarring and visual loss in a large percentage of these currently untreatable patients. This is based on a limited, early pilot study, and more extensive research will be necessary over the next several years. But we are encouraged that such treatment could preserve the visual independence and the quality of life for millions of older Americans.

On another front, basic research in retinal cell transplantation is making giant strides toward a potential therapy for macular degeneration, retinitis pigmentosa and other inherited retinal degenerations. Less than two years ago, scientists demonstrated that retinal epithelial cell transplants can halt one form of retinal deterioration in laboratory rats. Other NEI-funded investigators have now transplanted light-sensitive photoreceptor cells, which survived for at least six weeks, and produced opsin, a substance essential for vision. It may be many years before retinal cell transplant therapy in humans is a reality. But, the investment in such studies cannot be delayed if our nation is to reduce the ultimately greater burden of an aging population increasingly dependent upon family, government and philanthropic assistance.

The money that you appropriate for the National Eye Institute is the primary source of eye research support for all medical schools in the U.S., where the great bulk of such research takes place. I must respectfully point out that government support for eye research -- other than AIDS-related studies -- has not kept pace with annual inflation rates for the past three years. The value of NEI appropriations in constant dollars plunged from $140.6 million in 1987 to an estimated $131.5 million in fiscal 1990. This has meant not only fewer new grants awarded, but a double digit rollback on the funding of eye research grants already in place. Funds for some very promising and desperately needed studies have been cut for three years running. The cumulative impact has placed these projects in grievous peril of being reduced, needlessly prolonged, or discontinued, and risks discouraging productive scientists and losing them to other endeavors.

This disturbing trend is reflected in overall funding for the National Institutes of Health which -- with the exception of appropriations for AIDS research -- has barely changed since 1987. The rate of increase in constant dollars was only 1.5 percent in fiscal 1988 and 1.4 percent in 1989. It is estimated to be a mere 0.4 percent in fiscal 1990. At least two national surveys have found that the vast majority of Americans believe health research deserves much greater government support. The first, conducted in September 1988 by the Opinion Research Corporation, found that 82 percent approve of increasing federal health research spending, and 53 percent regard health research as the nation's top research priority. This widespread public support of research to eliminate the misery of disease was confirmed in a February 1989 Gallup Organization survey that found 87 percent believe the level of federal funding for biomedical research should be at least maintained or increased.

Eye diseases alone cost the American people $16 billion each year -- more than twice the annual amount this nation spends for all health research under the National Institutes of Health. The best way to reduce this staggering economic burden is to stop eye diseases from happening. Current techniques in genetics, biochemistry and molecular biology make it possible for the first time to identify fundamental causes, giving fresh new insight into the cure or prevention of many eye diseases. For example, discovery of the gene for a life-threatening childhood eye cancer, retinoblastoma, by NEI-funded scientists in 1986 revolutionized thinking on how some cancers are caused. Another team of NEI-supported investigators has now shown that copies of a healthy retinoblastoma gene inserted into retinoblastoma tumors grown in the laboratory caused the cancer cells to divide into normal tissue. This suggests that gene therapy may be possible for this eye disease and, perhaps, for cancers elsewhere in the body caused by other defective tumor-suppressor genes.

Such achievements illustrate the eye's unique potential as a laboratory for productive research relevant to many conditions affecting the rest of the body. Among its many attributes, the eye is the only organ where the vascular and central nervous systems are exposed to direct observation. Congress and the President have designated the 1990s as the Decade of the Brain, with the goal of focusing scientific and public attention on brain and neurosensory disorders. Each second the eyes and brain perform about a hundred billion "floating point logical operations" to produce the perceived images we call vision -- a task estimated to involve 40 percent of the brain. Visual neuroscientists have identified separate brain areas involved in the perception of form, motion, color and luminance, areas responsible for eye movements and their control, and still others that integrate visual information with eye movement and position. These on-going studies, along with current retinal cell transplant experiments, research to encourage optic nerve fibers to grow toward their target structures deep in the brain, and studies of the genes that control the wiring of nerve cells in the visual pathways could produce important benefits for rehabilitation after stroke, optic nerve damage, or other optic neuropathies.

Time restrictions permit only the most cursory discussion of today's achievements in the vast, diverse field of ophthalmic research. Nevertheless, a few brief examples may provide a hint of the extraordinary progress reported just in the past year and the enormous potential of vision research to lessen dramatically the devastating impact of blinding diseases upon millions of our citizens.

o Vision scientists identified the aberrant gene for one form of retinitis pigmentosa, which was found to produce a specific alteration in the molecular structure of the visual pigment -- an important clue that could lead to an effective treatment or prevention for this subtype of the disease.

o The mystery of where the eye gets the compound 11-cis-retinal, needed for the formation of visual pigment, was solved by investigators who tracked this substance to and defined the precise biochemical process by which it is produced in retinal pigment epithelial cells -- crucial information for the eventual prevention or treatment of night blindness.

o Eye researchers achieved new knowledge of the genetic basis for lens transparency, the biochemical changes that occur during cataract formation, and some of the environmental risk factors associated with cataract development. NEI intramural scientists are now developing lens cell culture systems to screen potential anti-cataract drugs that prevent or slow these sight-threatening changes.

o Therapy with the drug 5-FU was shown to have significant benefit in preventing scar tissue blockage of filtering channels after glaucoma surgery. Only 27 percent of glaucoma patients receiving the drug needed follow-up operations one year later as compared to 50 percent of patients treated with surgery only.

o A drug derived from botulism bacteria was found to provide safe and effective temporary control of the devastating eyelid contractions of blepharospasm and received final FDA approval. Studies now underway in animals suggest that the drug doxorubicin could provide permanent relief from the disorder.

o The intensive clinical investigation of ganciclovir proved this drug effective in reducing blindness from the cytomegalovirus (CMV) eye infection that affects at least 50 percent of AIDS patients. Current trials of foscarnet could lead to more effective drug therapy and avoid ganciclovir's main side effects.

o NEI investigators who isolated a unique protein from the surface of the white blood cells that cause uveitis, a potentially blinding inflammation of the internal eye structures, have now used that protein to halt experimentally-induced uveitis in animals. Comparable studies are underway to devise an oral vaccine to prevent uveitis in humans.

Mr. Chairman, advances such as these are the direct result of the wisdom and foresight Congress and this Committee have shown in providing support for the National Eye Institute and a national eye research program that in just two decades has done more to save human sight than was achieved in all prior history. The economic and social benefits of this progress cannot be overstated, and the fact that there are more opportunities for productive sight-saving research today than at any time in the past requires the rational allocation of funds for the 1990s.

In your determination of the total appropriation, we fervently urge the Congress to restore funds for construction of eye research facilities through the National Eye Institute budget. Many of our academic departments of ophthalmology have long ago outgrown their limited and obsolescent facilities. A survey conducted in 1988 by Research to Prevent Blindness revealed that more than 80 of these departments need to double the amount of research space available to them by 1995, either by renovation or new construction. They must increase their physical capacity for eye research by an estimated one million square feet at a projected cost of $300 million. Historically, total cumulative federal support for eye research construction has amounted to a meager $15 million. We strongly recommend that Congress appropriate $10 million, a relatively small amount, for eye research laboratory construction and renovation in the Fiscal Year 1991 budget of the National Eye Institute to help meet this long-standing deficiency.

The Administration Budget Proposal for Fiscal 1991 is an estimated 1.5 million in constant dollars below the 1990 appropriation, and would further erode National Eye Institute funding to the real dollar level of what it was nearly six years ago. It is my urgent request that this Committee recommend approval of the Citizens' proposed National Eye Institute Budget for Fiscal Year 1991. Our request contemplates expenditures in the following categorical program areas: for Retinal and Choroidal Diseases, $113,674,000; for Corneal Diseases, $39,081,000; for Cataract, $21,249,000; for Glaucoma, $22,998,000; and for Strabismus, Amblyopia and Visual Processing, $51,738,000. Within each of these programs, funds should be earmarked for clinical trials. We also recommend an appropriation of $34,810,000 for Intramural Research, Management and Program Services, and an additional $10,000,000 for Extramural Laboratory Renovation, Construction and Instrumentation, for a total budget of $293,550,000. Proposed expenditures in all categories are specified in the Financial Tables appended to my statement.

Our budget is a thoughtful extension of the detailed and periodically updated National Plan for Eye Research which has served as a model for research planning by other elements of the National Institutes of Health. Thanks to your strong support of this plan, and the vigor of its implementation by the National Eye Institute, the nationwide scientific program to preserve sight has at last acquired a momentum that is paying social economic dividends that far exceed the nation's annual investment in eye research. It would be disastrous at this point to impede that progress, which has opened unprecedented opportunities for productive research to end the dreadful burden of blindness.

I am grateful to have the opportunity to present this testimony and shall be pleased to respond to any questions. Thank you.

### NATIONAL EYE INSTITUTE FINANCING

| | Fiscal Year 1990 | Fiscal Year 1991 | |
|---|---|---|---|
| | Appropriation | President's Budget Request | Citizens' Budget |
| | (Dollars in Thousands) | | |
| *By Activity:* | | | |
| Grants: | | | |
| Research Grants | $178,462 | $186,416 | $224,070 |
| Laboratory Renovation, Construction and Instrumentation | 519* | | 10,000 |
| Core Grants | 6,613 | 6,613 | 9,000 |
| Individual Training | 2,389 | 2,389 | 2,778 |
| Institutional Training | 4,689 | 4,689 | 5,392 |
| Total Grants | 192,672 | 200,107 | 251,240 |
| Direct Operations: | | | |
| Intramural Laboratory and Clinical Research | 21,288 | 23,664 | 23,664 |
| Research and Development Contracts | 6,588 | 6,588 | 7,500 |
| Biometry, Epidemiology, and Field Program | 1,600 | 1,630 | 1,630 |
| Research Management and Program Services | 8,848 | 9,516 | 9,516 |
| Total Direct Operations | 38,324 | 41,398 | 42,310 |
| Total NEI Obligations | $230,996 | $241,505 | $293,550 |
| *By Program:* | | | |
| Extramural Research: | | | |
| Retinal and Choroidal Diseases | $ 91,163 | $ 94,535 | $113,674 |
| Corneal Diseases | 31,118 | 32,438 | 39,081 |
| Cataract | 16,870 | 17,650 | 21,249 |
| Glaucoma | 18,428 | 19,133 | 22,998 |
| Strabismus, Amblyopia, and Visual Processing | 41,162 | 42,939 | 51,738 |
| Laboratory Renovation Instrumentation, and Construction | 519* | ----- | 10,000 |
| Total Extramural Research | 199,260 | 206,695 | 258,740 |
| Intramural Research: | | | |
| Laboratory and Clinical Research, Biometry and Epidemiology | 22,888 | 25,294 | 25,294 |
| Research Management and Program Services | 8,848 | 9,516 | 9,516 |
| Total Intramural Research | 31,736 | 34,810 | 34,810 |
| Total NEI Obligations | $230,996 | $241,505 | $293,550 |

Note: Excludes funds for AIDS research consolidated in the Office of the Assistant Secretary for Health.

* To be transferred to other accounts for extramural construction in accordance with Public Law 101-166.

# NATIONAL INSTITUTE FOR DENTAL RESEARCH

## STATEMENT OF THE NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

Who will live? Who will die? Who will be given a chance for a normal life style and who will be forever physically and emotionally trapped much like real life "phantoms of the opera"? These are difficult questions but answers can be found if the Congress is willing to take appropriate action.

It is my pleasure to present this testimony on behalf of a very special patient population, that being those affected by an ectodermal dysplasia (ED) syndrome. ED, a group of over 130 genetic disorders, occurs in about one in every fifteen thousand births which places it among the orphan diseases. By definition the EDs are birth defects which involve abnormalities in at least two derivatives of the ectoderm (skin). Typically these include; absent or poorly functioning sweat glands; sparse hair follicles; abnormal finger and toe nails; and multiply missing teeth. Additionally other defects may be associated with the syndromes including missing limbs, mental retardation, clefting in the lip or palate, hearing and sight deficits, and malfunctioning sebaceous glands and mucous membranes.

Virtually nothing is known about the cause or causes of this group of birth defects and clinical care is often haphazard, predicated on guess rather than knowledge.

Ectodermal dysplasia is responsible for great inconveniences in the lives of those who are affected as well as for their families. The absence of sweat glands causes those affected to have little control over their body temperature. Physical activity and warm temperatures can be responsible for sudden, high fevers which negatively affect body function. In most cases an air conditioned environment is an absolute necessity at home, at school, and at work. The facial characteristics, lack of hair, and fang-like teeth are often the cause for teasing, staring, and incorrect assumptions as to the patient's mental capabilities. Emotional and financial distress, caused by the disorder and the expense of ongoing treatment, provide added concerns for our families. Everyone involved with the patient can expect to make alterations in their life style in order to accomodate the needs of the ED patient.

While families can and do accept the life altering effects of ED it is far more difficult to accept the lack of understanding of the disorder by those who provide care. Frequently obtaining an accurate diagnosis is incredibly difficult. ED babies have been put under heat lamps to try to make them sweat, a grave mistake. The potential damage from such a procedure is mind boggling. Others, well into their adult years, are still searching for someone who can tell them something about the strange set of symptoms which affect them. Once a diagnosis has been made, treatment can be the day's best guess rather than a thought out treatment plan. Physicians and dentists are often unsure of what to do and poor care choices result. Worst of all nearly 30% of the babies born with hypohidrotic ectodermal dysplasia, the most common form of ED, die in their infancy. This is a disease group about which precious little is known and for which even less is being done.

Among patient treatment needs are; improvements in clinical diagnosis, satisfactory solutions for recurring infections, appropriate dental care and reconstructive procedures, as well as answers for problems in the areas of dermatology, ophthalmology, and otolaryngology. Though the EDs are well recognized as dermatologic defects, little is known about the basic skin defect responsible. It is obvious that both basic science and clinical research is needed in order to give these patients a chance to live more normally.

What then should be done? The continued commitment by the Congress to our National Institutes of Health is commendable. However, that commitment must be assigned a high priority not only in our minds but in our pocketbooks. I urge the members of Congress to affirm quality health care as basic to the rights of all citizens by monetarily supporting the need for expanded health research throughout the National Institutes of Health.

Small organizations which represent orphan diseases will never be able to raise the funds necessary to support the costs of research. For example, our organization provides limited funding for a genetic study underway at the University of Oregon which is well on its way to localizing the gene for x-linked hypohidrotic ectodermal dysplasia. Such information will allow for carrier identification, the diagnosis of newborns, and family planning based on knowledge rather than guess. Our excitement for the propects of this project is great, however, the reality is that the project is in danger of extinction due to a lack of funding.

While that news is disappointing there is a bit of good news to share. Clinical research, currently underway at the National Institute for Dental Research, may be the singular most important study regarding dental implants in the world. This unbiased, objective project is the first to assess the safety and efficacy of implants in individuals as young as aged 12. The results of the project will be of great importance not only to those affected by ED but to anyone who looses permanent teeth prematurely. My own son will soon become a participant in the study, an opportunity for which we are most grateful. Although much good will be gleaned from the implant study far more must be done.

It is totally unacceptable for a nation that spends in excess of $500 billion per year for health care to allot only 3% of that amount towards finding cures or preventatives. Unsolved medical questions remain just that....unsolved. The costs incurred continue day after day, year after year, with no end in sight. However, cures and preventatives bring to an end unnecessary costs and the ongoing cycle of repeated inappropriate or ineffective care.

The only acceptable answer to the problem is an increase in the number of grants funded by the National Institutes of Health. Not only is the current 1 out of 5 funding rate for approved projects unacceptable, it may well lead to an even more frightening situation, that of bright minds choosing careers other than medical research. It is my firm belief that we are indeed at a crossroad where we either choose a commitment to research and the health of the American public or we accept mediocrity both in the scope of research being conducted and those doing the research. To choose anything other than quality research and researchers would be foolhardy.

It is at this point in time that I wish to encourage the Congress to fund the National Institute for Dental Research at a level of $210 million dollars. Such a level of funding, while still not fully addressing the needs, will allow for a more suitable award rate and will serve to encourage young scientists to persue research as not only a challenging profession but one which will also allow for a reasonable standard of living. Surely great minds are as deserving of our financial commitment as are great athletes. The folks at NIDR have a hugh research mission to fulfill. Currently their areas of concern include; oral cancer, AIDS, periodontal diseases, craniofacial birth defects (including cleft lip and palate), diseases with oral soft tissue ramifications, chronic pain, restorative materials, dental implants, dental care for the aged, and caries. As the scope of the Institute broadens it can not be expected to address research needs with an ever dwindling capability to provide research funding. No one in their right mind would bake a pie to serve six and then invite twelve people for dinner. Similarly we can not expect this Institute to solve more and more problems without sufficient resources. NIDR, through its excellent record of research success, has proven the ability to solve crucial health questions. Now we must followup with our full financial support.

Our National Institutes of Health are a true gem. It is unfortunate that the American public has so little knowledge of the exciting work being done there. My visits to NIH always leave me with great respect for all who are a part of this phenomenal governmental agency. You'll not find parking lots filled with exotic vehicles, nor employees dressed in glamorous clothing. Conversations are not of how to obtain pay raises or aggravation with lengthy work days. Rather one hears real concern for the future of medical research, ideas on how to stretch every dollar so that every possible grant can be funded. What we have is an incredible group of people with an unswerving commitment to research excellence. One can only wonder how effective all government facilities might be if similar loyalty was given by all employees. NIH and the National Institute for Dental Research have earned not only our respect, but they are most deserving of our support. I urge you to fund NIDR at a level of $210 million thereby insuring not only a bright research future but bringing hope to scores of Americans waiting for cures and treatments.

# NATIONAL CANCER INSTITUTE

## STATEMENT OF THE AMERICAN ASSOCIATION FOR CANCER RESEARCH

Chairman Harkin and Members of the Subcommittee, my name is I. Bernard Weinstein. I am Director of the Comprehensive Cancer Center of Columbia University, President Elect of the American Association for Cancer Research (AACR), and a physician/scientist with 30 years of research experience in the areas of cancer causation and prevention.

I am delighted to have this opportunity to represent the American Association for Cancer Research and present testimony on behalf of increased funding for the National Institutes of Health and specifically, to support a budget of at least $2.4 billion for the National Cancer Institute (FY 1991). As I will discuss in detail, this level of funding is the minimum required to protect the scientific integrity of the Institute and to maintain this country as a leader in cancer research. Indeed, failure to increase the National Cancer Institute's budget to at least this level will have disastrous consequences.

The AACR is this nation's major professional society dedicated to cancer research. It represents over 6,000 basic science and clinical cancer researchers. Our members are located at medical schools, universities, hospitals, research institutes, and government laboratories throughout this country. They conduct innovative and fundamental basic and clinical studies on cancer causation, prevention and treatment. Their mutual goal is that cancer may some day be eradicated - a goal certainly shared by this Committee and the American public. Our Association tremendously appreciates the Federal biomedical research program, which is dependent upon Congressional support and provides about 90% of the total support for cancer research in this country.

Without the past and ongoing support of this Subcommittee and the fine leadership which has been provided by both the Chairman and the Subcommittee members, the NIH would certainly have suffered the types of dramatic cuts which were experienced by some other Federal Agencies. As a result of your support, the program of the National Cancer Institute is acknowledged, worldwide, as the leader in cancer research. On behalf of the members of the AACR, as well as the many cancer patients alive today as a result of our research efforts, we wish to thank you for your past and continued support of this major institution. At the same time, our Association is impelled to remind this committee of the major crisis that this country now faces in terms of inadequate support of cancer research, and biomedical research in general.

Let me first remind you of the tragedy and magnitude of the cancer problem by describing the following recent case seen at our medical center. A 45 year old woman was admitted with a large mass in her left breast. Diagnostic studies indicated that she had a highly malignant breast cancer that had already spread to the regional lymph nodes and the liver. Initially the tumor responded to therapy, but later the tumor recurred and she died within two years. Autopsy revealed extensive invasion of the tumor in the liver, brain and skeleton.

This tragic death is not a rare episode. Each year over 40,000 American women die of breast cancer and there are over 140,000 new cases of invasive breast cancer. Indeed, the disease is so prevalent that unless we greatly expand our research efforts, one out of eleven American women are destined to develop this disease. If the tragedy of breast cancer is not itself a sufficient reason to increase federal funding for cancer research, then let me remind you that deaths from breast cancer account for only 8% of all cancer deaths. The total number of cancer deaths in this country - including cancers of the lung, prostate, colon, etc. - is over 500,000 per year. This means that 1 out of 5 Americans living today will eventually die of some form of cancer, again unless we work together to reverse this unnecessary and tragic destiny.

At the same time, progress in cancer research at both the basic science and clinical levels has reached an exciting crescendo, but we must provide more resources to capitalize on these advances. The irony is that, despite this monumental challenge and the exciting new opportunities, we have recently witnessed a crippling reduction (in real dollars) of the budget for the National Cancer Institute.

I now want to mention a few of these exciting advances, which were made since the passage of the National Cancer Act in 1971.

### 1) Cancer Causation and Prevention

Epidemiologic and laboratory studies indicate that at least 80% of human cancers are due to environmental (external) factors. This is an extremely optimistic message since this means that most cancers are, in principle, preventable. The human species is not destined to suffer a high incidence of cancer. Indeed the identification of cigarette smoking as the major cause of lung cancer (which accounts for about 30% of all cancer deaths), and the subsequent institution of smoking cessation programs, has already led to a reduction in the incidence of this disease. The identification and control of man-made chemical carcinogens has also led to reductions in the incidence of cancer of the bladder, lung and liver. Evidence is accumulating that dietary, hormonal and life-style factors play a role in the causation of breast, colon and prostate cancer. Thus, more intensive research could also lead to the prevention of these major forms of cancer.

Unfortunately, the current level of funding is inadequate to pursue new leads to human cancer causation, or to mount vigorous cancer prevention programs.

2) Oncogenes and Suppressor Genes

Basic research has led to the identification of oncogenes (cancer-causing genes) and also growth suppressor genes which inhibit tumor growth. Specific growth factors and the biochemical circuits inside cells that control cellular growth and differentiation (called signal-transduction pathways) have also been elucidated. These advances provide new and profound insights into cancer causation, and specific tools for cancer diagnosis and staging. They also open the door to new and more rational strategies for cancer treatment. Indeed the 1989 Nobel prize was awarded to Drs. Michael Bishop and Harold Varmas for the discovery of oncogenes in the mid 1970's. Advances in this field have been supported almost entirely by NIH funds.

Increased funds are now required to translate these fundamental findings into clinical applications. Without such funding these new insights into the fundamental nature of the cancer cell will remain dormant.

3) Biological Response Modifiers and Biotechnology

Fundamental advances in immunology and molecular biology, coupled with biotechnology, have also led to novel and exciting approaches to cancer treatment. These include the spectacular studies using lymphocyte-activated killer cells and interleukin-2 therapy, the development of interferons and colony-stimulating factors, and the use of tumor-specific antibodies that can be specifically targeted to cancer cells. Advances in bone marrow transplantation coupled with the use of colony stimulating factors also provide exciting new approaches to cancer therapy.

Again, inadequate funds are available to support these fundamental advances and to support the necessary, but expensive, clinical trials.

As an aside, let me remind you that the research supported by the NIH has spawned the entire biotechnology industry - a major new biomedical and economic force in this country and abroad. At a time when we are concerned about the vitality of this nation's industry and economy, we can take pride in this striking example of the spin-off generated by the NIH research program. Thus, increased support of the NIH program is one of the best investments this nation can make in its future.

4) Adjuvant Therapy and Chemotherapy

During the past 20 years major advances have been made in the treatment of breast cancer, a disease which you will recall strikes one out of every eleven American women. The disfiguring radical mastectomy procedure has been replaced by lumpectomy followed by radiation therapy or chemotherapy. Advances are also being made in the treatment of more advanced stages of this disease. At the same time the institution of mammography programs has led to the detection of breast tumors at an early stage when treatment is much more effective. Recent studies on oncogenes in human breast cancer suggest new methods to assess the malignancy of specific tumors. This could provide a method for predicting which tumors will respond to specific forms of therapy. Thus, there is hope that the type of tragic case of breast cancer described earlier in this presentation will not occur in the future.

Just within the past year results have been published indicating that adjuvant therapy (with a combination of drugs) of colon cancer, a disease which is the second most common cancer in the United States and one which thus far has been quite resistant to chemotherapy, holds great promise. As you know, within the past twenty years striking advances have been made in the treatment of leukemia in children, childhood tumors, Hodgkin's disease and cancer of the testes in young men.

The above-mentioned exciting progress in cancer therapy indicate the opportunities for even greater advances, if adequate resources for drug development and clinical trials are made available.

This year the Ad Hoc Group for Medical Research has recommended an overall NIH budget of approximately $9.2 billion, which would include $2.4 for the NCI. Our Association vigorously supports this proposal as the absolute minimum level of funding which the Congress will accept. We are on the brink of major biotechnological breakthroughs, not only in cancer research but in many areas of biomedical research. Our basic science efforts are paying off. A long-range investment must be made in support of the NIH. The National Cancer Advisory Board has transmitted to the President the FY 1991 By-Pass

Budget (a "needs" budget) for the NCI, of approximately $2.4 billion. This is the level of funding which our Association believes is the absolute minimum required to maintain a viable cancer research program. A program that will pursue the exciting new research opportunities that I have mentioned. The President's FY 1991 Budget Request, however, falls about $800 million short of this level. As you know, this $800 million shortfall is about the cost of one B-2 bomber, and a $2.4 billion NCI budget would be less than 1% of the total defense budget. At a time when everyone agrees that, because of the easing of political tensions in Eastern Europe, the defense budget can be cut, certainly we can find these critical funds. Although one frequently hears concern about this nation's financial deficit, there is insufficient concern about this nation's physical and intellectual health. If we neglect these vital resources this nation will enter the twenty-first century with much more serious deficits.

As a result of recent curtailments in the NCI budget, the fundamental structure of our National Cancer Program is now being threatened. For example, after the passage of the National Cancer Act in 1972, 60% of all approved meritorious research grants submitted to the NCI were funded. Under the FY 1991 President's Budget it is estimated that less than 20% of the approved grants will be funded. Already, only about one-fifth of all approved NCI grants are being funded. This is a disaster. Throughout this country brilliant young investigators are being informed that their research grant applications have been "approved but not funded." In addition the President's Budget would have the following drastic effects:

* The overall number of grants supported by the NCI would be reduced by 10%.
* Budget cuts in the form of "downward negotiations" would be placed on 20% of competing grants and 5% of noncompeting grants.
* There would be no growth, and actual reductions in development and support of this nation's cancer centers and cancer prevention and control programs.

I want to also stress that research training, and science education in general, play a crucial role in our efforts to solve the cancer problem, and to biomedical research in general. They are also critical to the vitality of this nation's economy and intellectual life. And yet we are witnessing a very serious deterioration in science education and in the science training of young Americans at all levels, from grade school on into postgraduate training. In cancer research we are already experiencing a shortage of well-trained young American scientists. To an increasing extent we are calling upon foreign trained students to staff our cancer research laboratories. This is a crisis situation. Unless we reverse this trend by expanding NIH funded training programs, and science education programs in general, we will not have a new generation of cancer researchers who can capitalize on the exciting advances made in the past 20 years. It is absolutely critical that we strengthen this investment in the future. The By-Pass Budget would provide increased support for research trainees. This is essential. At the same time, this nation must also undertake other major initiatives to improve science education and research training in this country.

If the $2.4 billion By-Pass Budget is funded, the NCI could provide the following essential support:

* Full funding at a 50% award level for approved competing research grants;
* Full funding for noncompeting research grants;
* Full funding to the existing cancer centers, restoration of funds to 10 centers phased out in 1989 and 1990, and funding to 5 new cancer centers;
* Expansion of the application of new advances in molecular biology to cancer prevention and treatment;
* Expansion of the number of clinical trials;
* Increased funding for studies on cancer in minorities and in the 65 or over population in this country;
* Expansion of cancer prevention and control programs;
* Expansion of cancer information dissemination activities; and
* Expansion of the biological modifier approach to cancer treatment.

While this would be a significant improvement over the President's proposed budget of 1.6 billion, I want to stress that it is a "no frills" budget. There is also an urgent need for major construction funds to remedy the deterioration of this nation's cancer research laboratories. Many of our cancer research laboratories have antiquated physical facilities or are overcrowded, and yet these are the facilities which are expected to produce state-of-the-art medical breakthroughs. For over ten years we have we have not had significant federal funding to support laboratory renovations or new construction projects. There is also an urgent need to establish a long-range budget for biomedical research in this country. Our perspective must be shifted from year-by-year budget crises to long-range planning. We must assure that the NIH maintains its preeminent role in providing the new knowledge that will lead to the prevention and/or cure of major diseases, like cancer, that threaten all Americans.

In summary, despite the magnitude of the cancer problem and the exciting opportunities that are now available to make major advances in cancer prevention, diagnosis and treatment, this nation faces a major crisis because inadequate funds are being provided to address these problems. As I mentioned before a 2.4 billion budget for the NCI and a total NIH budget of 9.2 billion represent only a small fraction of the federal budget when compared, for example, to the Defense budget. Furthermore, the potential cost savings from this investment in biomedical research are immense. It is estimated that the total direct costs of health care for cancer patients in the United States for 1989 is $33.5 billion. A $2.4 billion NCI budget is less than 8% of this amount. The harvests of this research effort could lead to enormous cost savings, in addition to the relief of human pain, suffering and unnecessary tragic deaths. Thus the NCI's investment of $55 million to develop a chemotherapy regimen for testicular cancer, a disease which strikes young adult men and was previously fatal, now results, each year, in annual savings of $150 million. I am certain, therefore, that we can count on the support of this Subcommittee to provide the same level of dedication and commitment to the support of biomedical research which you have demonstrated in the past. If I or my colleagues in the American Association for Cancer Research can be of assistance to Members of the Subcommittee, please do not hesitate to call upon us.

Thank you for your time and the opportunity to appear before this committee. As always it has been a privilege for the American Association for Cancer Research to present testimony before the Labor/HHS/Education Subcommittee. I would be happy to answer any questions.

# NATIONAL CENTER FOR NURSING RESEARCH

## STATEMENT OF THE NATIONAL ASSOCIATION OF PEDIATRIC NURSE ASSOCIATES AND PRACTITIONERS

The National Association of Pediatric Nurse Associates and Practitioners (NAPNAP) is pleased to present written testimony on our association's views regarding federal funding of nursing education and nursing research programs.

### National Association of Pediatric Nurse Associates and Practitioners (NAPNAP)

NAPNAP represents over 3,000 nurse practitioners who specialize as pediatric, family, or school nurse practitioners. Pediatric nurse practitioners manage a broad range of health care services for infants, children and adolescents, including the management of colds, ear infections and other common childhood diseases. They staff well-baby clinics, administer immunization and screening programs, and teach parenting skills, growth and development, nutrition and safety.

### Pediatric Nurse Practitioners (PNPs)

Currently, a PNP is a Registered Nurse who completes a formal continuing education/certificate program and/or masters program in nursing. Program content includes courses in growth and development, family and cultural issues, pediatric physical and developmental assessment and common childhood illnesses and problems. After graduation, a PNP can obtain professional certification, which is a confirmation of professional competency. Many of our members practice in areas which are underserved by the traditional medical services team. In order to fund the advanced education requirement to become a pediatric nurse practitioner, many of our members have benefited from the federal funding of nursing education available through Title VIII of the Public Health Service Act.

### Funding Recommendations for Nursing Education

The President's budget request for 1991 for nursing education is $5 million. Inadequate funding recommendations for nursing education are not new to either our association, the nursing community, or Members of this Subcommittee. We are very appreciative of the support Congress has demonstrated over the last twenty years in providing funds to increase enrollments in schools of nursing and to assure the financial viability of nursing education programs.

of nursing and to assure the financial viability of nursing education programs.

Currently, the Division of Nursing is authorized to spend $13.432 million for institutional and individual educational support to nurse practitioners and nurse-midwives. For Fiscal Year 1991, NAPNAP urges the Subcommittee to appropriate $15.4 million for the nurse practitioner/nurse-midwife education line item. In addition, our association supports the request of the Tri Council for Nursing for $69.05 million for all the nurse education act programs. This small increase recognizes the difficult budget constraints all Americans are being asked to respect yet addresses the shortage of qualified nurses in the following ways: educates more nurse practitioners and certified nurse-midwives; establishes and supports innovative curricula for educating these professionals; educates nursing faculty in improved methods for recruiting and educating minority and disadvantaged students; establishes educational programs in underserved areas; and provides funds to students, in return for which they will provide service in underserved areas.

We believe the return on this investment is substantial. Today's health care environment calls for the maximum use of health care professionals educated to listen, to teach, to diagnose and to treat patients in a flexible and cost-effective way. Nurse practitioners, with educational preparation in both nursing and medicine, are meeting these needs in hospitals, homes, clinics and agencies all over the United States.

## Funding Recommendations for Nursing Research

The National Center for Nursing Research (NCNR) promotes research in nursing practice which contributes to the health of all Americans and saves health care dollars. The Center represents nursing science concerns as part of the National Institutes of Health by performing intramural and extramural research. The President's budget request for 1991 is $35.127 million. The National Association of Pediatric Nurse Associates and Practitioners recommends a budget allocation for 1991 at $42.5 million--a reasonable request at a time when the institute is still in its initial growth phase. This budget allocation is also supported by the Tri Council for Nursing and the Nurses' Coalition for Legislative Action. Funding at this level will restore 1990 cuts in competing and noncompeting grants and will allow for increases in research trainees, career awards and noncompeting grants. This year is also the first year the institute will conduct intramural research. The program, done in collaboration with the National Institute of Allergy and Infectious Diseases and the National Institutes of Health Clinical Center is an AIDS research program and will start on a small scale with $202,000 dollars.

## Summary

Pediatric nurse practitioners urge Members of Congress to fund nursing education and research programs for FY 1991 at levels to 1) ensure sufficient numbers of nurses qualified to provide a full range of nursing and health care services, and 2) ensure adequate funding for nursing research and research training vital to promoting excellence in the science of nursing.

# ANIMALS AND RESEARCH

## STATEMENT OF THE AMERICAN HUMANE ASSOCIATION AND THE COMMITTEE FOR HUMANE LEGISLATION

The American Humane Association, the Committee for Humane Legislation, the Massachusetts Society for the Prevention of Cruelty to Animals, The American Society for the Prevention of Cruelty to Animals, The Animal Protection Institute, The Doris Day Animal League, the National Alliance for Animal Legislation and the Humane Society of the United States request appropriations in the amount of $13 million for FY'91 for the Biological Models and Materials Resources Program, National Center for Research Resources at the National Institutes of Health.

The Biological Models and Materials Resources Program (BMMR) was established by NIH to fulfill, in part the mandate of Congress as expressed in the Health Research Extension Act of 1985 (P.L. 99-158). This program was established to provide for the development and support of non-mammalian models, such as cell systems, lower organisms, and nonbiological systems for biomedical research. Non-mammalian model systems can, and do, provide opportunities to advance the understanding of biological processes, and may provide valuable insights into mechanisms of biological function.

The FY'88 funding levels for BMMR were at $2.584 million and they were increased in FY'89 $3.75 million.

There was an increase in funding to $5.364 million in FY'90. The budget request for FY'91 is for $5.356 million dollars.

With this small amount the BMMR funds various centers, awards grants and contracts for services related to the development of non-animal alternatives for biomedical research. BMMR also supports the American type culture collection, which distributes 100,000 cultures and micro-organisms to researchers each year. It also supports the Yeast Genetic Stock Center which maintains and distributes over 900 strains of the yeast Saccharomyces cerevisiae. This yeast is used in the complex genome project.

The small increase in funding for BMMR in FY'90 enabled the program for the first time to use $749,000 for an RFA (Request for Application) to award investigative grants on research proposals. The FY'91 request is for $787,000 for this purpose. We believe this is not an adequate amount.

At the above funding levels, in FY'90 BMMR would be able to fund only 4 - 6 investigative grants at an average of $100,000 - $150,000 direct costs per grant. We believe BMMR's funding level should be increased to allow it to fund at least 30 investigative and on-going grants at funding levels of $250,000 per grant.

We therefore urge this committee to add an additional $7.7 million to the centers request in order to fund these additional grants. This would increase the total funding for the BMMR program to $13 million dollars.

Those of us in the animal protection community strongly support the development, validation and use of alternatives to animals in testing. (The term alternatives refers to the reduction of the numbers of animals used, refinement of protocol to reduce pain and suffering and replacement of animals with appropriate non-animal models.) The Congress has supported research into the development of alternatives in the past and we hope will continue to do so by increasing the funding levels for this worthwhile program.

## STATEMENT OF THE HUMANE SOCIETY OF THE UNITED STATES

As scientists with The Humane Society of the United States (HSUS), we are submitting testimony on the funding of animal research at the National Institutes of Health (NIH), the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA), and the National Toxicology Program (NTP). The HSUS is the nation's largest animal protection organization, with over one million members and constituents. We have earned a reputation for moderation on the issue of animal research by promoting methods of research that either reduce, replace or refine traditional animal tests. Today, we are particularly excited about the opportunities for alternatives that are being opened up by the NIH, ADAMHA, and NTP. We are hopeful that our enthusiasm will be shared by a broad spectrum in Congress and the general public since these alternatives hold great promise for both human and animal health and welfare.

### National Toxicology Program

As you know, the NTP is an interagency program specializing in toxicity testing. Its participating agencies include NIH's National Institute of Environmental Health Sciences (NIEHS), the Center for Disease Control's National Institute for Occupational Safety and Health (CDC/NIOSH), and the Food and Drug Administration's National Center for Toxicological Research (FDA/NCTR).

NTP is perhaps the focal point for research on the development and validation of non-animal testing methods in the federal government. The HSUS requests that this subcommittee direct the NTP to devote more of its resources to the development and validation of non-animal alternative methods.

The NTP's interest in non-animal methods stem from the program's mission. According to the NTP's Review of Current DHHS, DOE and EPA Research Related to Toxicology, Fiscal Year 1989 (hereafter, Review, FY89)

> The development of faster, more reliable, and more predictive of adverse health effects assays is a central function of the National Toxicology Program. (p.3)

The Office of Technology Assessment characterized non-animal methods as usually faster, more reliable, and less expensive than animal testing, in its report, Alternatives to Animal Use in Research, Testing, and Education, issued in 1986. Congress has agreed that non-animal methods have practical as well as humanitarian advantages over animal-based methods (see, for example, the preamble to the 1985 Dole/Brown amendments to the Animal Welfare Act).

The NTP itself underscored its interest in the practical advantages of procedures such as alternative methods in its Fiscal Year 1989 Annual Plan:

> A...major...objective is to develop, improve, and validate more sensitive, rapid, and less expensive methodologies for detecting and characterizing the toxicity of chemicals. (p. 42)

The NTP realizes there is a commonality of interests in alternative testing methods by the animal protection community and the federal agencies involved in chemical testing. Each year for the past few years, the NTP has included a chapter on the 3Rs of replacement, reduction, and refinement in its annual plan. The most recently published plan (for FY89) states:

> Program scientists continue to seek more precise, more rapid, and less expensive ways to develop the (toxicological) information. Although this (practical) orientation is central to their scientific investigation, it is often complemented by the interest in the need to decrease the number of animals used in research for humanitarian, as well as scientific and economic, reasons. (p. 33, emphasis added)

The NTP plan goes on to describe alternative tests that the NTP-participating agencies are currently developing. The NIEHS is developing 12 sets of alternative methods, the NIOSH 6 sets, and the NCTR 11 sets. Most of the assays involve *in vitro* cell cultures or microorganisms and invertebrates.

The NTP's budget consists of voluntary allocations from the three participating agencies (NIEHS, NIOSH, NCTR), the amounts of which are specified in memoranda of understanding after yearly appropriations are known. NTP's current budget is $82 million, with roughly $20 million allocated for the development and validation of new methods. The new methods can be either non-animal or animal-based, so the agency is spending some fraction of $20 million on new alternatives. According to the latest figures available (NTP's *Review*, 1989), this $20 million allocation was provided principally (90%) by NIEHS, with NIOSH supplying the balance.

Methods development can be broken down into the development of new methods and their subsequent validation. NTP funding for development has expanded from $15.2 million in FY87 to about $18.5 milion in FY89. Unfortunately, funding for validation, without which new methods cannot be applied, fell over the same period from $2.3 million to $2.1 million. This downward trend should be reversed.

The HSUS has the following recommendations regarding the NTP:

* Funding for the development of new methods (specifically alternatives methods) should continue to be expanded.

* Funding for the validation of new methods (specifically alternative methods) should be increased substantially, reversing the recent downward trend.

* In the area of developing and validating new methods of chemical testing, the NTP should be directed to concentrate on alternative methods to the greatest extent possible.

The HSUS would appreciate this subcommittee's efforts in stipulating these requests to the NTP-participating agencies.

NIH Alternative Program

The HSUS strongly urges that BMMR be allocated $7.7 million more than its FY91 request of $5.356 million, for a total of $13 million. As you know, the Biological Models and Materials Resources (BMMR) Program was established by the NIH to fulfill the mandate of Congress as expressed in the Health Research Extension Act of 1985. The program is designed to develop methods such as cell culture, invertebrate studies, clinical studies, and mathematical modeling that may reduce the use of laboratory animals. Such studies involve investigation of cells grown in the test tube, insects and molluscs, human patients, and computer simulation. BMMR received $2.854 million in FY88; $3.75 million in FY89; and $5.364 million for FY90. BMMR's modest request for FY91 is for $5.356 million.

The bulk of BMMR's funding is utilized for supporting various research centers such as the American Type Culture Association, which distributes 100,000 cell cultures and microorganisms to researchers each year. BMMR also supports the Yeast Genetic Stock Center which maintains and distributes over 900 strains of the yeast Saccharomyces cerevisiae. Previously, little of BMMR's funding was available for supporting grants for developing new alternatives.

However, the increase in funding in FY90 allowed BMMR to use $749,000 for a Request for Applications (RFA). The RFA was sent to thousands of working scientists across the nation, and as the director of BMMR tells us, "the response has been overwhelming." While BMMR is requesting $787,000 for the RFA during FY91, The HSUS feels that this amount does not do justice to the program. We have reviewed the projects funded under the FY87 and FY88 program announcements and are pleased to report a dramatic improvement in the quality of projects funded in 1988.

It is our opinion that this NIH alternatives program is slowly becoming a focal point within NIH for biomedical discovery. In the past, the lion's share of NIH funding has long been allocated for data production: experimentation on animals and ill human beings. With so much emphasis on experimentation, there has been little incentive or opportunity for analysis of the vast storehouse of data that has been amassed since the end of World War II. It is well known among biomedical scientists that it is easier to get a grant from the NIH to experiment than to analyze data.

Yet data analysis is critical to discovering mathematical or computer models that describe how the human body works in health and disease. Many of the projects now funded under the NIH alternatives program are for mathematical models that probably never would have been funded by the traditional NIH study sections. For instance, the reknowned scientist who pioneered the first comprehensive model of the human immune system had applied to the NIH in 1987 for a grant to develop his computer model. While Dr. Melvin Cohn of The Salk Institute is among the most respected immunologists in the world, his request was turned down flat. It was not until 1988, when Dr. Cohn submitted his grant proposal to the NIH alternatives program, that his computer model was finally funded. He tells us that many of his peers in the biomedical community are skeptical that the immune system can be explained in simple mathematical terms.

We have spoken with many gifted mathematical modellers working at some of the leading research institutions across the nation and they all tell the same tale: it is nearly impossible to get a grant from the NIH for mathematical modelling or computer simulation. So you can see that the issue of alternatives to animal research is as much a public health problem as an animal protection problem.

For that reason, we believe that a dramatic increase in BMMR funding is more than justified by its potential for animal and human health. The HSUS strongly urges that BMMR should be allocated $7.7 million more than its FY91 request of $5.356 million, for a total of $13 million. This would allow BMMR to increase the number of grants funded under its program from roughly 6 per year to 30 per year (at $250,000 per grant). HSUS scientists would be happy to provide you with additional information to support this recommendation.

Alcohol, Drug Abuse, and Mental Health Administration

While we support the overall proposed funding increase for ADAMHA in FY91, The HSUS is concerned about any potential increase in funding for addiction research on animals.

The HSUS recently received a report from the pollsters Penn and Schoen Associates which indicates that nearly 75% of the American public is opposed to addiction research on animals. We believe that much addiction research on animals is seriously flawed from a scientific standpoint.

For instance, we believe that using animals to test the "addictive potential" of various drugs is both ineffective and inhumane.

During the 1970s, the National Institute of Drug Abuse's (NIDA) scientists tested cocaine on primates for potential addictiveness in a variety of experimental situtations. Under some conditions, the primates would press a lever to inject themselves with cocaine; in an equal number of cases, the primates would not press a lever to inject themselves with cocaine. In those cases where primates did press the lever, researchers were not sure whether the primates pressed the lever because they had become addicted or because they had become overstimulated by the cocaine.

For that reason, NIDA scientists did not list cocaine an an addictive drug in the standard texts in the 1970s. As late as 1981, NIDA head Dr. William Pollin proclaimed that cocaine, while dangerous, was "not physiologically addicting." It was not until the human cocaine epidemic of the 1980s that NIDA finally listed cocaine as an addictive drug.

There could be no clearer example of the uselessness of animal studies of addictive potential. Yet addiction experiments still constitute the bulk of NIDA's animal studies. The poor quality of its research programs is one of the main reasons NIDA was singled out by the White House Conference for a Drug Free America in 1988 (as reported in The Washington Post on June 29, 1988) for failing to live up to its mandate.

In addition, patient advocacy groups such as the Parents Resource Institute for Drug Education (PRIDE) are highly critical of NIDA research. Mr. Thomas Gleaton of PRIDE, who was one of the White House conferees of 1988, said of NIDA researchers, "They're more interested in getting more research dollars than they are in the health of the nation."

While we would never make such an accusation, we do urge this Committee to seriously reconsider the need to support addiction research using animals. We believe that the public would be better served if the increased outlays for addiction research were funnelled to projects that combined sophisticated in vitro systems with clinical studies. Such research offers the main promise for improving treatment of drug addicts and alcoholics, for which both Congressman Silvio Conte and Senator Joseph Biden have been working over the past year. While we applaud Congressman Conte's efforts in creating NIDA's Medication's Development Program, we recommend that the program concentrate its resources on alternatives to animal research.

In fact, due to recent breakthroughs in the field of alternatives, we feel that animal testing is no longer necessary to discover drugs for the treatment of addiction. As you may know, NIDA no longer uses animals to "screen" for potential antiaddictive drugs. NIDA has largely switched to in vitro tests in its quest for antiaddictive drugs.

According to Dr. Marvin Snyder of NIDA, they now use a battery of in vitro tests called NOVA-SCREEN developed by the NOVA Corporation in Baltimore. NIDA contracts with NOVA to screen potential antiaddictive drugs. Pharmaceutical firms that are interested in anti-addictive drug development are encouraged to develop drugs shown effective either in the in vitro tests or in their own clinical trials. It is only at this stage in the process, after the potential antiaddictive drug has been discovered, that animal addiction experiments may come into play. The company may test the potential antiaddictive drug on addicted animals in order to convince the FDA that is is indeed efficacious.

Although the FDA does not explicitly require animal efficacy testing (unless the drug had proven hazardous in prior animal safety testing), many firms do the animal efficacy tests to ensure that the drug is approved for human use. In general, the drug company does not test the drug on addicted animals until it is committeed to getting the drug into human trials with human addicts (because of prior findings in vitro or in patients). In the case of the new antialcoholic drug known as busiprone, its manufacturers are performing animal addiction tests concurrently with tests on human alcoholics.

It is therefore apparent that the animal efficacy tests are not an absolute prerequisite to human trials, on either scientific or legal grounds. It is our opinion that the animal addiction experiments are performed for legal reasons rather than for scientific reasons. We object to any animal experiment that is not performed strictly for scientific reasons. NIDA would do well to use AIDS drug development as a model for its own program, as Senator Biden's staff pointed out in Pharmacotherapy: A

Strategy for the 1990s. Drugs for AIDS are generally tested in vitro and, following careful testing for safety, promising candidates go directly into human trials. We would favor such a streamlined strategy for antiaddictive drug development. In sum, we hope that this Committee will stipulate that NIDA hold the line on increased expenditures for animal addiction research, particularly in its Medications Development Program. We feel that both human addicts and laboratory animals stand to benefit from the shift in emphasis from animal studies to alternatives to animal research.

In conclusion, The HSUS seeks the support of this subcommittee in promoting alternatives to animal research.

# CHRONIC FATIGUE SYNDROME

## STATEMENT OF WILLIAM T. HARVEY, M.D., M.P.H.

Mr. Chairman, I submit this testimony as a medical professional trained in Public Health, as a patient with Chronic Fatigue Syndrome, or CFS, and on behalf of family members, co-workers, and friends who have this illness. Chronic Fatigue Syndrome also carries other names such as Chronic Epstein-Barr Virus Syndrome and Atypical Poliomyelitis. In other English-speaking nations, it is known as Myalgic Encephalomyelitis.

I am aware that the 1989 Labor-HHS-Education Appropriations Bill, accompanied by report number 100-127, urged the NIH and Social Security Administration to expand activities related to CFS. The Centers for Disease Control was also funded for a modest expansion of surveillance of this illness. I am most grateful to this Committee and its staff for this response to Chronic Fatigue Syndrome.

It is my intent in this statement to discuss three important aspects of CFS. The first is the individual suffering caused by the illness. The second is my experience that CFS is widely prevalent nationwide, is infectious, and is growing. The third is that CFS is a real illness, now supported by serious research data, and is an urgent Public Health matter.

In the fall of 1987, I was working for a major Aerospace firm in California, responsible for the design and development of that firm's bid on the Health Maintenance Facility for the national Space Station Program. Following an outbreak of a "flu-like" illness in November, I and six other individuals on the program developed symptoms consistent with CFS. It was to be 6 months before I was able to name my illness, despite experience and formal training in worldwide infectious diseases as an Air Force Flight Surgeon.

The symptoms that I initially developed were similar to a severe case of influenza. They included severe muscle aches, unremitting headache, fever, "lightheadedness", and profound fatigue. These symptoms were overlaid with a total loss of my usual sense of well-being. For the next three months this sickness persisted, without remission, and I was bedridden for much of that time.

In February of 1988, three months into the illness, the "influenza-like" bouts became intermittent, but rapidly returned if I attempted exercise of any sort. Between periods of forced bedrest, I continued to feel ill in a global and difficult-to-define way.

During this phase of the illness, other symptoms began to appear. My heart rate became rapid, and I was continually aware of pounding in my chest even at rest. Headaches became daily experiences, beginning shortly after noon, and were unremitting until early morning, despite narcotic-strength medication. Sleep became impossible without hypnotic drugs. Low-grade fevers and night-sweating were common. Frequent and recurrent outbreaks of of cold sores and mouth ulcers began, and were to continue for the next two years.

Although painful and frightening, these physical symptoms were not the worst part of the illness. Far more frightening were the sensory and neurologic symptoms that began concomitantly with the physical symptoms, and paralleled them in intensity. Hearing sensitivity was diminished and accompanied by continual "ringing" in both ears. Vision was seriously impaired in low-light, with loss of clarity, persisting images, and "night-blindness". Sensations of pain and phantom touch occurred regularly on the skin surface and throughout muscle tissue. Both taste and smell were altered intermittently.

The symptoms that finally disrupted my professional career and my private flying were cognitive. My ability to remember recent events became seriously impaired, as did my attention span. Both became serious enough that I could no longer accomplish my work. Despite judgment difficulty, I recognized some of my impairment, and withdrew from employment in July, 1988.

These same cognitive difficulties resulted in near-disaster in mid-1988 on two solo flights, when I became disoriented and unable to follow the tower operator's instructions. Both flights ended successfully because of skillful ground-controller handling. The second flight was my last to date.

My constellation of symptoms is virtually identical to those of the other two hundred-or-so CFS patients whom I personally know or have interviewed. The only differences are in the order of symptom intensity and the overall degree of illness severity. The severity ranges from mild to total disability, with most patients unemployed and partially-functional. The illness seems to be lifelong, and yet it is not directly fatal. In each of us, it has been, and is, an unending nightmare, and is impossible to fathom unless and until you become afflicted with it. The closest analogy to help your understanding is to imagine the worst case of influenza you've ever had. Then imagine that it never ends. Add to that neurologic, cognitive, immunologic, and inflammatory complications. This is Chronic Fatigue Syndrome.

Having the illness, however, has been only a part of the CFS nightmare for me and most other patients. Most physicians are totally unaware of this illness. Many who are seem to believe it is psychological in origin, and in particular, is clinical depression. Until recently, it had no name, no identifiable causative agent, no recognized treatment, and no believable data. Prevalence is unknown. It is no wonder that, confronted with such a bizarre constellation of multi-system complaints and "normal" standard laboratory tests, the average physician could offer only ignorance or assurance. Many also chose, unfortunately, to offer discounting and rejection. For this reason, many CFS patients I have met have necessarily found their way to "fringe" practitioners, and are being treated with worthless remedies.

Despite widespread medical ignorance of this illness, my experience is that it is unexpectedly common. It simply remains "hidden" because of that ignorance. When traveling, visiting my home town, attending conferences, and even in my neighborhood, I have found people who have CFS. It is now easy for me to recognize. I simply look for those who have dropped out of work, have stopped exercising, or who talk of strange symptoms their physicians can't account for. I confirm my guess by having them complete an evaluation using the CDC 1988 criteria for CFS at one of the few regional clinics that are aware of the illness. In any group I have encountered in Texas, California, or Mississippi, I have not failed to find less that 1 or 2 CFS patients in a hundred; usually 4 or 5. Many have only recently contracted the illness.

My experience is that CFS is clearly infectious. My wife, also a physician, contracted the illness about ten months after I did, presumably from me. I have met several families where more than one member has the illness; most contracted it in a serial fashion. Recent evidence presented at *The First International Conference on Chronic Fatigue Syndrome and Fibromyalgia*, February, 1990, of studies done at the University of Pittsburgh School of Medicine, support this observation.

Data is now appearing in serious medical peer-review journals, by recognized researchers, supporting the reality of Chronic Fatigue Syndrome. This data is indeed verifying the basis for the bizarre symptom-complex of CFS. Expectedly, evidence of cerebral dysfunction has been found both by cognitive testing and by SPECT and PET scan. Another expected finding is consistent immunologic abnormality. An unexpected and frightening aspect of the immune dysfunction is lowered Natural Killer cell function. A study done by the Pittsburgh Cancer Institute in evaluating a small cluster outbreak of CFS revealed several cancer deaths within two years, implying an increased risk of cancer in this population 27 times normal. Other studies are underway, addressing the etiology of clinical symptoms and early attempts at treatment. They remain, unfortunately, few in number, and are supported primarily by donations from CFS patient support groups, or funds siphoned from grants for related illnesses.

In summary, Chronic Fatigue Syndrome is an illness that is both a reality, and a living and often unending nightmare for those who have it. In my experience as a physician, it remains a hidden yet major cause of human suffering. It appears to be incurable, or may persist for many years. It may also be responsible for many related cancer deaths.

In my experience, CFS is extremely prevalent in the helping professions, among teachers, and those who have a high frequency of human contact in their employment. I am encountering an inordinately large number of highly educated professionals with this illness, many with graduate-level education. From my experience alone, it is clear that the social and economic impact of this illness on society is already significant.

Judging by the rapidly increasing numbers of CFS support groups, medical articles, and media attention, I can only conclude that this illness is spreading. Considering the high cost of diagnosing diseases "by exclusion" (as is CFS), and the higher cost of current partially-effective CFS treatment with expensive antivirals and Human Immune Globulin, its economic impact on the health care system is already great, and is likely to become much greater. The reality of this illness must not be denied, despite our medical ignorance of it. It is imperative that we address its existence, its prevalence, and its cause, treatment, and eventual cure. To fail to do so now will only exaggerate its eventual consequences.

Recently, at the Santa Barbara Writer's Conference, I was talking to three other people with CFS. Two also had doctorate degrees; one was a doctoral candidate. I was suddenly struck with the talent of the people I know with this illness. None of them were complaining about their illness, and all had attempted to remain productive despite their suffering and greatly diminished physical limits. None could continue full-time employment. This is when I really began to sense the magnitude of the impact that CFS is having on the productivity of this society. And why one day its understanding and cure will return a great amount of that productivity.

I, like others providing statements to this Committee, am concerned that the activities of the NIH, the CDC, and the SSA are grossly insufficient in light of the magnitude and impact of this illness on our society. I concur in offering the following suggestions to the Congress to expand Federal activities related to the Chronic Fatigue Syndrome:

To expand and better coordinate research into CFS, the National Institutes of Health should be funded to establish a multi-center research consortium including a centralized reference laboratory and data center ($822,000); should be funded to conduct a CFS medical research conference; should be directed to designate a senior official to coordinate NIH CFS-related activities; and should significantly expand its extramural activities, both nationally and internationally.

To continue planned epidemiologic and related activities, the CDC should be funded above current levels to conduct case-controlled, immunologic, virologic, rheumatologic, genetic, toxic, and long-term follow-up CFS studies (at least $600,000 additional).

To improve responsiveness to disabled CFS patients, the Social Security Administration should be directed to update, using current medical research data, its guidelines for disability evaluation of CFS.

## STATEMENT OF AMANDA MARTIN

I am testifying on behalf of those (over 300 individuals in Minnesota alone) whose lives have been dramatically altered by a pervasive, persistent and enigmatic disorder we currently call Chronic Fatique Syndrome, or CFS. I write this with the hopes of encouraging you to continue your committment to fund further medical research in this area and to investigate, in order to improve, access to exisiting health care programs for sufferers with chronic, enigmatic diseases.

My story is not uncommon among those afflicted with CFS; I have been called adventurous, ambitious and committed. I traveled the world, worked and did research in Europe and the United States, published papers, directed my own program, served in the Peace Corps, lobbied for reform of Minnesota laws, obtained a master's degree and experienced the professional fields of health care delivery, counseling, acting and teaching by the age of thirty. Up to that time, I believed that whatever physical ailment met me would be faced, treated, learned from, and then, left behind.

Consequently, four knee surgeries taught me to recover from an acute problem with optimism, determination and discipline. Mononucleosis, my first year in college, taught me to use my time wisely between periods of rest. Malaria, paratyphoid, giardia, amebia and chronic diarrhea reenforced the need for patience and maintenance of a naturopathic diet. These lessons carried me through until I returned from the Philippines with unshackable lethargy and proneness to constant bacterial and viral infections. I requested the Department of Tropical Medicine at the University of Minnesota to consider my medical history, yet, they found no correlation between my current status and recent history. I strengthened my diet, continued to work and actually improved to swim and bike six days a week, racewalk, work fulltime as director of an adult prototype leadership program, actively socialize and pursue a graduate degree. Life was quite full and purposeful. I was happy.

However, this life change abruptly in September, 1987 when the lethargy returned accompanied by sore throats, Herpes Simplex One, painful, leadened fatigue, and a marked inability to concentrate and track conversations. I was diagnosed with strep throat and mononucleosis with high titer levels to the Epstein-Barr virus. Thinking I could manage this problem by working intermittent hours I continued directing the leadership program. Yet, within a month it became clear that I could not carry-on. Supervisory and teaching responsiblities were extremely difficult to manage; more than two people conversing became very confusing to me, my memory was not reliable, and managing simple budgetary responsibilities became impossible since I could not consistently calculate even simple figures. Climbing stairs, cleaning, and cooking, were extremely difficult tasks and left me exhausted and unable to function. Driving was a risk to me and everyone on the road. I had no choice. I had to quit work, and I had to be taken care of. I moved home to my parents and entered the underworld defined by this illness: enormous joint and muscle pain, painful, pulsating lymph glands throughout my body, burning eyes, leadened limbs, fevers, headaches, sleepless nights, mindless days and intermittent depression, punctuated with isolation.

After one year of rest, I improved enough to begin the battle for Social Security Assistance. Besides being denied for assistance for the year I had not been able to work with the claim that I could have worked, "...at the same level of my previous position.", I was also told that this illness was precipitated by "..depression." Nothing, besides the physical pains of CFS, can be more devastating to a patient than hearing this. Not to be outdone by such an inaccurate claim, I filed again, only to be denied again. I had to find a way to pay for my expenses. Having no other form of financial support, and despite knowing that I was not fully recovered, I pursued and found a part-time position. Although I may be luckier than most to be able to work a bit outside the home, I regularly battle CFS symptoms and any bug or virus traveling (in) my way, and I miss, on the average, one day a week with this part-time position.

Despite what I learned and applied from my previous, varied, health maladies to manage CFS, this recalcitrant disease requires more; it requires respect, and honesty, among and between CFS sufferers and health care professionals, and it requires your unquestionable support. I join in the collective voice of representatives from CFS/CFIDS support groups throughout the country strongly urging you to increase funding for research, public education, and improved access to health care programs. I, particularly, urge you to fund medical research within and between the allopathic, public health and naturopathic communities. Together they and CFS sufferers can provide insight, treatment and hopefully prevention of this vulturous, debilitating disease.

Thank you for your consideration.

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## LETTER FROM THE UNIVERSITY OF CALIFORNIA, IRVINE

February 23, 1990

United State Senate
Senate Office Building
Washington, D.C.

Mr. Chairman:

I am sending you this testimony, for the record, as a physician engaged in research and clinical management of patients with chronic fatigue syndrome, which has affected a sizeable population in the United States. I have spoken at several national and international conferences dealing with this subject, including the International Epstein-Barr Virus Conference at Rome and the most recent conference at Milwaukee, Wisconsin. Furthermore, I will be giving an invited lecture at the conference on this syndrome in Cambridge, England, in April 1990.

The chronic fatigue syndrome (CFS) is a syndrome of symptom complex. Criteria for its diagnosis have been established by the Centers for Disease Control. The diagnosis is still based largely on the patient's symptoms and to some extent physical examination by the physician. Therefore, "history"(his-story) is absolutely crucial and clinicians should 'listen' to their patients. At the present time, the cause(s) of CFS is unknown and therefore, the treatment of this syndrome is to relieve the symptoms. Although a number of dysfunctions of the immune system have been observed, only a few of them form the basis of treatment to relieve the symptoms. For example, a fair proportion of patients fail to make appropriate antibodies when immunized with pneumococcal bacterial vaccine, lending support to a specific antibody defect, to which some patients respond by treatment with intravenous gammaglobulin.

The chronic fatigue syndrome is challenging to the investigator and frustrating for the patients and treating clinicians. It is challenging to the investigator, because we have good reason to believe that this syndrome is heterogenous with regards to its causes and only through rigorous research CFS can be defined and "objective/investigative" criteria for diagnosis can be formulated. From the clinician's point of view, it is frustrating, because there is no known definite cause of CFS and there are no laboratory tests to follow a patient; therefore the treatment becomes empirical. I believe the most important frustration is for the patients, the majority of whom are intelligent, high achievers, who hold good jobs, and who in spite of major symptom complex (often losing their jobs because of serious fatigue, lack of mental concentration and disturbance in recent memory) cannot get proper help. Furthermore, the health insurance agencies are not helpful either. In patients who show specific antibody deficiency in laboratory tests and are appropriately given intravenous gammaglobulin resulting in improvement of the patient's symptoms, in the majority of cases the insurance company will refuse reimbursement, compounding the problem of the patient.

In conclusion, Mr. Chairman, I would like to emphasize that we are faced with a poorly-understood debilitating illness affecting a sizeable population of the U.S. who need the help and support of your committee. This will require appropriate funding for critical research in CFS to understand its etiology and pathogenesis. It is through critical research that this disease could be 'objectively' diagnosed and appropriately treated. Funds should also be allocated for a few well-designed treatment protocols (double blind) at major medical centers.

With best regards,

S Gupta

Sudhir Gupta, M.D., Ph.D.
Professor of Medicine, Neurology, Pathology and Microbiology and
Molecular Genetics, Chief, Division of Basic & Clinical Immunology

## STATEMENT OF THE WISCONSIN CFS ASSOCIATION

Good morning! My name is Lee Janzen. I am here representing the Wisconsin CFS Association and also on behalf of the parents of CFS patients.

You've just heard my daughter Shannon briefly tell you what her life has been like for the past 3 years. What she has said is very true.... only 10 times worse.

She has battled the doctors, parents, school personnel, some family members and friends. At one point in her medical treatment, 3 of her doctors were collaborating to have her hospitalized for depression. Many CFS sufferers have gone though this also. The doctors were unable to find any conclusive results in the battery of tests they had done on her so they felt that it must all be "in her head". She had gone through multiple blood tests, catscans, ultrasounds, and x-rays. I refused to let them do a spinal tap. They called in the psychiatrists. At that point, i had had enough. We walked away from them all. We left the physical therapist who did not understand why Shannon cried when they hurt her while trying to stretch her muscles. We walked away from the psychiatrist that specialized in children and teens who relied heavily on anti-depressants that left Shannon in another world. We walked away from Shannon's pediatrician who had treated her for 13 years and didn't know what else to do for her. Our quest for a knowledgeable doctor was to begin once more.

I have talked to many patients of CFS and many parents. I have even talked to a patient who had been given a brain biopsy because her doctor was searching for a "clue" to her malaise. She was eventually diagnosed as having CFS, as was her 2 young daughters. Sadly enough, many families have more than 1 sufferer among them. Many of these sufferers have battled their own employers and insurance companies. Also, we have fought for Social Security benefits. But one of my most lengthy battles as a parent has been the public school system.

When Shannon was first sick, we tried to get her homework from classmates, teachers, and counselors. I would drive to her school during my lunch break and pick up assignments by the dozens and projects that were suppose to be done.... if you had a microscope or a telescope at home. Otherwise, she would get an incomplete! Then I tried the Homebound tutoring program. Things went downhill fast. If the teachers, tutors, and school officials don't understand children with chronic illness they don't know how to educate them. That's the BOTTOM LINE. These kids don't always look sick. You can't always see their swollen hands and glands. They don't hear them up throughout the entire night because one of the symptoms of CFS is insomnia. They also suffer from terrible headaches, blurred vision, poor concentration and usually on some form of medication for infections or other symptoms. My daughter also suffers from fiborcytis, an inflammation of the tissues surrounding her muscles. This makes it hard for her to even hold a pencil on some days, and other days impossible. I have explained this to many teachers and tutors but they still demanded that Shannon keep up with her assignments. Because of these problems with the school systems, many of our children will end up with a very limited education. Some will not finish school.We need to educate our schools, our tutors, our teachers and each other if we want our children to have an "educated chance" in this world. The majority of these kids want to be in school. The thrill of being home is long gone. They want to hang out and have friends. They want to be involved in school activities. I would have liked Shannon to have a "normal" life as a teenager. Instead, she has 1 friend left from all of the ones she once had. One good friend is better than none...and I've talked to some young people that don't even have that 1 friend left any more. I've also been in contact with parents whose child is so sick that they see no future for themselves or any reason to go on. if we don't pay attention to what is going on here... we could have an epidemic of suicidal sick children and teens. THIS IS CRITICAL! The more mail that we receive, the more I am aware of how desperate the situation is and it is becoming worse on a daily basis.

I feel, from a parent's point of view, saddened that the battles have just begun for my child. They haven't gotten better. If anything, the more I learn, the more I know I need to learn. Listen to us speak out to you and appeal for help. When you help us you help the young people of our nation. There are thousands of CFS teens and children. There are many more that have not been diagnosed yet! Education of CFS is the key to open the door for researchers and victims, for parents and patients. Please help us to find a cure and the cause of this terrible disease. We need research money and educated school personnel. We especially need to educate the medical community. I want to be able to tell my daughter and her friends that they have a future and their opinions count. Help me to help them. We will all win in the long run with such a dedicated commitment to our children of today....our leaders of tomorrow.

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## STATEMENT OF JUDY BASSO

I am writing this testimony for the record, because I am a patient stricken with Chronic Fatigue Syndrome (CFS), as well as president of the Chronic Fatigue Syndrome Association of Minnesota and a member of the steering committee for the forming United Federation of Chronic Fatigue Syndrome / Chronic Fatigue and Immune Dysfunction Syndrome / Chronic Epstein-Barr Virus Organizations. In spite of extreme limitations caused by the illness, I try to be productive by volunteering some of my low energy to help other patients.

It is very frustrating for me to see the tremendous suffering and devastation caused by CFS. I come in contact with hundreds of people who have this horrible illness and wish you could listen to all of their stories first-hand. For most CFS patients, every aspect of their lives has been drastically impaired. What remains of previously active, talented, intelligent, and motivated individuals is a tragic shell of human existence. A bright twenty year old patient, sick since 14 and too ill to complete high school even with homebound tutors, describes it well: "This illness not only isolates you from life, but from all the things you love to do." Adjusting to the effects of CFS takes tremendous courage and constant strength. The ever-present requirement for rest destroys the opportunity for very productive individuals to fully participate in life.

My story is a typical one in many ways. In my former life, as I have come to call my healthy years, I taught junior high math full time. I was actively involved in professional, community and social organizations, holding several leadership positions. I ran 40 miles a week, played power volleyball, racquetball and golf. I was an avid cross-country skier, loved to bike and was working toward a career change, preparing to take the CPA exam. In November 1983 at the age of 36, I contracted acute infectious mononucleosis. After a month of bedrest, I thought I was well and returned to work. I found out quickly that I was wrong. I remained so sick, I used up ten years of accumulated sick days during the rest of that school year. During this time no doctor acknowledged that I should have a medical leave of absence from my job. At the end of summer vacation my health seemed to improve for several weeks. I was able to work a full eight-hour day, although my energy level was still not up to par. Then my symptoms recurred and I had a relapse which was more severe than the initial mono. I have been unable to work ever since.

Now over six years later, CFS still forces me to spend most of my time lying down. Walking any distance is more than I can tolerate and I frequently need to use a wheelchair. I cannot carry heavy groceries or clean my own house and rarely can cook meals from scratch. Most routine tasks of daily living are a struggle and result in a worsening of my symptoms. I pay a great price for every expenditure of energy. My social life has changed from participating in sports to phone conversations from my bed or the couch. I have to carefully ration my energy in order to see a movie with a friend or spend an evening at a restaurant. Even with the best of planning, I cannot predict in advance if I will be able to attend such social outings. Many relationships important to me have dissolved because a once-common bond no longer exists. A former friend remarked, "It's too difficult for me to see you like this."

More frightening to me than the physical impairment is the fact that I often experience what I refer to as "brain fog". Anytime I try to function like a healthy person, the overwhelming fatigue, weakness and malaise increase, and my ability to think straight stops. My memory is unreliable, and I can no longer do simple math calculations accurately. Sometimes I become so confused that I get lost driving familiar routes, cannot process information people are sharing with me or track a simple conversation.

My future financial security is questionable. I receive about $9000 a year in Social Security Disability Benefits and while I am grateful for that, it is minimal compared to what I would earn as teacher or hoped to earn as an accountant. The procedure for me and other CFS patients to successfully qualify for these benefits was very slow, frustrating and often humiliating. Rather than acknowledge how devastating life without work was for a career-oriented individual with an employment record since high school, the judge at my hearing kept inquiring if I was trying to use the system to avoid working. He failed to ask me any details about my medical condition. While I did not expect to be treated with the compassion I deserved, I was completely unprepared for the shame I experienced that day. The attorney and rehabilation expert who represented me were outraged by the inappropriate comments and questions from the judge.

When I talk to parents of children with CFS, I feel fortunate that I was in my mid-thirties when CFS destroyed life as I knew it. If my health does not significantly improve, I believe I will survive because I have developed good coping skills and am resilient by nature. I have learned to focus away from the losses I have experienced and to appreciate the lessons I have learned as a result. I try not to project what lies ahead, but the thought of children continuing to be so ill is terrifying and particularly sad. They cannot regain lost years of energetic play, social development and education. This Christmas, a sixteen year old who contracted CFS at the age of ten, spent the holiday alone. He encouraged his family to visit their relatives without him, because he knew he was so ill he would end up sleeping all day. He had joined his family when they opened presents Christmas Eve at home, and that was simply too much activity for his condition.

The fact that so little is understood about the syndrome causes great distress to patients and frustrates physicians. Long-term prognosis, causative agent or agents, mode of transmission, those likely to be at risk, genetic predisposition and other factors involved, an effective treatment, and cure are all unknowns. The working case definition and the surveillance study by the Centers for Disease Control are important steps in the right direction. Basic CFS research in the fields of virology, immunology and neurology is long overdue and desperately needed. The lack of a definitive diagnostic test or marker for the illness allows skepticism from some medical professionals and complicates research studies.

The Honorable Rudy Perpich, Governor of Minnesota and an honorary member of the Chronic Fatigue Syndrome Association of Minnesota board of directors, recently initiated a resolution addressing CFS to the National Governors Association. Recognizing the suffering, serious losses to society and economic drain caused by this disabling condition, the governors unanimously call for Congress and the White House to increase the coordination of research into this disorder and to foster a greater understanding of CFS within the public health community.

On behalf of CFS patients in Minnesota and across the nation, I want to thank the Committee for its commitment to significantly increased research funding for the furtherance of knowledge about this life-wrecking illness.

## STATEMENT OF THEODORE W. VAN ZELST

Mr. Chairman and members of the Committee, my name is Theodore W. Van Zelst. I am presenting this testimony for the record as president of Minann, Inc., a foundation which has been active since 1984 on matters related to the disease defined by the Centers for Disease Control as Chronic Fatigue Syndrome (CFS), also known as Chronic Fatigue Immune Dysfunction Syndrome (CFIDS).

The National Institutes of Health and the Centers for Disease Control have been active in studying this disease. Private researchers, funded by foundations, individuals, medical centers and hospitals have also been studying CFS. Despite these efforts, the differential diagnosis of Chronic Fatigue Syndrome remains difficult. There is confusion regarding treatment, modality, and a cure is not yet in sight. Those afflicted by the disease are desperate and need hope that there will be an end point to their pain and a promise for a healthier future.

Hundreds of self-help support organizations have been developed around the country. There are strong regional groups active in giving patient support and disseminating information about the disease. Most state and regional support organizations are now publishing newsletters. Some are very extensive in their coverage and contain stories on current research and support activities.

The fight against Chronic Fatigue Syndrome is unusual in that patients, in spite of their debilitating illness, have had to take a leading role in efforts to educate physicians and the general public. Patients have been active in conducting surveys to obtain more information about the disease in order to make the data available to medical researchers. A number of new books on the disease have appeared. One book, *Hope & Help for Chronic Fatigue Syndrome* by Karyn Feiden discusses the emergence of the disease, the medical perspective, the search for diagnosis and possible treatment; another book, *Waiting To Live* by Greg Fisher has been updated and reprinted.

Recognition of CFS as a disease has finally arrived at the public level. The national support organizations are becoming stronger. State and regional groups strengthen the network. Books and articles are appearing regularly. The popular prime-time TV show "Golden Girls" devoted two episodes in September, 1989 touching every facet of the CFS illness with sensitivity and understanding. Each time a CFS media story appears, more physicians become aware of the existence of the disease and many more patients are identified.

The concern about this disease has been outlined by the National Governors' Association which passed a Resolution at its February 1990 meeting. The Governors' Resolution tells us much about Chronic Fatigue Syndrome and its research needs:

> ***"The nation's governors call on Congress and the White House to foster greater understanding of, and to better coordinate research into, the disease, Chronic Fatigue Syndrome.***
>
> ***The governors recognize that there is an urgent need to expand the public health response to this disease, which has been identified in every state, and which the Center for Disease Control has called an emerging epidemic. Estimates of the afflicted range as high a 1.5% of the populace, or approximately 3,750,000 individuals.***
>
> ***Recent biomedical research has identified Chronic Fatigue Syndrome as a serious illness that affects a number of systems of the human body including the immune system. The syndrome is characterized primarily by chronic debilitating fatigue and is often accompanied by a variety of cognitive dysfunctions. Victims of this syndrome often experience symptoms of sufficient severity to legally qualify for Social Security Disability.***
>
> ***The apparent increase in this disease during the 1980s argues for better exchange of information about Chronic Fatigue Syndrome between concerned Federal and State public health authorities.***

> ***Therefore, the governors call on Congress and the White House to act to increase the coordination of Chronic Fatigue Syndrome research and programs within the public health community for the exchange of information about this disease."***

As a result of this Resolution a number of governors have proclaimed CFS Awareness Weeks and some cities have taken similar action.

The Social Security Administration has moved forward in understanding Chronic Fatigue Syndrome, but much more must be done. Patients still experience refusal of disability benefits, delays and cut-off of benefits. The SSA coverage of CFS can be greatly improved by its issuance of directions or regulations to the nationwide staff and by expanding and clarifying its coverage of CFS in the Operations Manual. Past history indicates that such actions would most likely stimulate similar clarifications on the part of third party insurers. Such clarification would ease the current confusion regarding insurance coverage. The SSA should be directed to make an Annual Report to Congress regarding its handling of CFS claims matters.

Progress is occurring in the CFS research arena and some researchers are encouraged. There have been new findings which may lead to a better understanding of the disease. New research reports are expected to appear in medical journals in the near future.

Important meetings have been held during the past year. In October, 1989 the Great Lakes/Midwest CFS Conference was held in Milwaukee, Wisconsin. The First International Conference on Chronic Fatigue Syndrome and Fibromyalgia was held in February, 1990 at Los Angeles, California. In April, 1989, 550 physicians, nurses and health care professionals attended the San Francisco Chronic Fatigue Syndrome Conference. There were many smaller meetings and workshops. The First World Symposium on CFIDS will be held in Cambridge, England, April 1990.

One researcher, Director, Harvard's Brigham & Women's Hospital, Anthony L. Komaroff, M.D., reported at the Milwaukee meeting that

> ***"..to me and to other researchers it continues to seem likely that there is more than one cause of this condition (CFS). ...I think that a variety of different microbes -- viruses, bacteria and others -- may be involved in CFS."***

Scientists in government laboratories, medical schools, hospitals and medical research centers studying CFS have many theories as to its cause. There are experiments with treatments using a variety of drugs, and studies related to the incidence of this disease as well as to its development in an individual. It is generally believed that CFS is a multi-system disease, affecting the central nervous system, cardio-vascular system, neuro-muscular system and immune system. CFS affects patients in different ways and at different times with varying degrees of severity, thus the wide range of symptoms.

It is not the purpose of my presentation to this Committee to attempt to recommend any one research direction. However, it is apparent from the many communications that we receive from patients and researchers, reports about CFS in medical journals and in the support organizations' newsletters, that more research is needed.

During 1989 the NIH awarded two research grants to study CFS. Research and patient communities believe that more extra-mural funding is needed. Nationwide, more researchers are active. Now is the time for the NIH to issue more extra-mural research funds to qualified medical and scientific researchers active in the study of CFS who may have the idea or basic concept that can lead to a diagnostic technique or treatment.

Also in 1989, the CDC began a CFS Surveillance Program now underway in Atlanta, GA; Grand

Rapids, MI; Reno, NV; and Wichita, KS. The program has enlisted the help of many sentinel physicians in these areas. The Program compares and contrasts the actual and estimated incidence of CFS in the four cities being studied. Many feel that there the Surveillance Program should be expanded to more cities.

Additional funding is needed for the CDC to conduct familiarization meetings for physicians and to circulate information about this disease. Apparently many physicians are not up to date on the CDC's latest definition of CFS as published in the March 1988 issue of *Annals of Internal Medicine*.. Reports from around the country indicate that many CFS patients have difficulty receiving proper payments from insurance companies, because the companies and their advisory medical staff do not understand CFS. Many physicians who treat CFS patients are being denied payment by insurance companies.

Dr. Roper, Director of Centers for Disease Control, reported in an Overview Hearing (3/22/90) that last year $1.2 million was spent on CFS research by the CDC. With increased funding over that base, the CDC could expand its surveillance and research programs. Physicians and health professionals have to be educated about this disease. An additional $1,250,000 should be allocated for educational activity to enhance awareness of CFS and to facilitate patient care A central clearinghouse should be set up for the tremendous amount of data being developed; and a CFS patient registry should be started.

The constraints of the Federal Budget make it impossible to achieve all of the objectives of governmental and private scientists who are studying CFS. We believe that the NIH and CDC can take the initiative and leadership to consolidate and coordinate CFS research activity by:

1) Recommending standardized instruments for collection of clinical data
2) Systemizing the evaluation of functional health status, according to standardized and validated instruments
3) Advising regarding the establishment of a Standardized Protocol for laboratory tests
4) Providing for storage of both sera and leucocytes for future testing

Some research studies have indicated that a patient's chronic fatigue may be associated with a well recognized organic or psychiatric illness. In an Overview Hearing (3/21/90) it was reported that the National Institute of Child Health & Human Development (NICHD) and the National Institute of Mental Health and the NIAID are working together on CFS research. This cooperative effort is applauded. However, medical and patient committees are not generally aware of these studies. The NIH should take steps to make them aware through its *Backgrounder* and other publications. The many CFS newsletters would welcome stories on this cooperation. The cooperative studies should be expanded.

Because of the widespread nature of this disease, the involvement of a great number of scientific researchers, the indication of great numbers of persons afflicted with CFS, it would be appropriate for the NIH to designate a senior official to assist in coordinating CFS activities nationwide by maintaining close contact with the CFS researchers who have the latest scientific knowledge available about CFS studies.

The NIH should study the future establishment of a multi-center consortium of institutions involved in the care and study of patients with Chronic Fatigue Syndrome. It would be appropriate for an organization of the status of the NIH to organize such a center.

In past testimony we have suggested that the NIAID make effective use of the existing Small Grants Fund and expedite the issuance of these grants to recognized CFS researchers. NIAID recognizes the existence of this fund, but there is little or no activity related to CFS. Small funding in specific study areas can open up new avenues of research which may lead to discovery of a treatment or cure for this disease. $500,000 should be made available for these Small Grants.

WE URGE THIS COMMITTEE TO DIRECT OR RECOMMEND:

The National Institute of Allergy & Infectious Diseases (NIAID):

1) Expand its internal research studies on Chronic Fatigue Syndrome (CFS).

2) Expand funding for extra-mural research on CFS. Issue more RFAs in such areas as etiology, patho-physiology, medical treatment, and interplay with allergy and neurological involvement.

3) Make available $500,000 for Small Grants on CFS research.

4) Continue the program of workshops and support of meetings for dissemination of information about CFS.

5) Study the advisability of conducting research or data accumulation of continued immune dysfunction on CFS patients who are presumed to be in remission.

6) Study the future establishment of a multi-center of institutions for study and care of CFS patients.

7) Present an Annual Report to Congress on CFS research expenditures, research progress and opportunities.

8) Expand NIAID cooperation in basic CFS research with :

National Cancer Institute, National Institute of Mental Health
National Institute of Child Health & Human Development

The Centers for Disease Control (CDC):

1) Continue and expand CFS surveillance (possible added sites) and epidemiology activities.

2) Conduct Chronic Fatigue Syndrome case control studies in surveillance areas.

3) Expand immunologic studies, virologic studies, toxic studies and conduct long term follow-up review of CFS patients identified in the Surveillance Program.

4) Continue CFS public and health professional information, training and research activities and allocate for this public relations and educational activity: $1,250,000

Social Security Administration (SSA):

1) Issue directions or regulations regarding treatment of the claims of CFS patients.

2) Study the establishment of a central clearinghouse for CFS data and start a CFS patient registry.

3) Make an Annual Report to Congress on SSA handling of CFS claim matters.

On behalf of the dedicated CFS researchers, the expanding number of patients and their supporting families, we thank this Committee for its attention to this growing national health problem. We ask that the Committee continue its efforts in support of CFS studies so that research will lead to answers about this debilitating syndrome which affects the lives of so many of our citizens.

## STATEMENT OF JEAN COLE

For the record my name is Jean Cole. My two sons and I are living in a terrible kind of limbo, and none of us know how long we will be held here. We have an illness called Chronic Fatigue Syndrome. Both cause and cure are totally unknown.

Every day for us is a new battle with extreme weakness, fatigue, severe headaches, fevers, muscle pain, joint pain, chest pain, and sore throats. We also experience memory problems, dizziness, and difficulty concentrating.

My son Steve is seventeen. His old friends are enjoying classes, dates, sports, jobs, and are looking forward to senior year. Most of them have forgotten about him now, because he has not been in class with them for almost four years. He had been in gifted classes, played football, and was half way to his black belt in karate. He could have written his own ticket to the future. Now Steve is only able to be out of bed for a few minutes a day. His waking hours are spent in bed, where he watches TV or visits with people over his computer modem. There are times when he is too ill for even these activities. He tried to do his schoolwork at home, but is too weak and too lacking in concentration to study. He can rarely read even for enjoyment. He has the same hopes and dreams that other teenagers have, but he has no idea how long his future will be on hold. Homecomings, proms, state tournaments, dating, chemistry class, and report cards have all passed him by. He can never have them back. He has been ill for six years, and doesn't know if he'll ever be well.

My son Jim is fourteen. He has been ill for about two years. Like his brother, he could have been in gifted classes. He was known by everyone for his quick smile. He loves nature and animals, and used to ride his bike for hours through the park reserve near our home. He had a natural strength and agility that showed promise for gymnastics. Now he studies at home, taking correspondence courses. He has trouble with concentration, and has short-term memory problems. It is taking him two years to complete eighth grade. His face is white, and shows the strain of chronic illness. Due to probable metabolic disturbance from the illness, both Jim and his brother are far underweight. The once-lively Jim is now slow-moving, frail, and short of breath. He wants to get well so that he can become a therapist. He also wonders when and if that will happen.

Our daughter was born with a rare form of autism. The family all worked with her to help her break through to the world. We were told by the "experts" that she would never be able to function in the world. We brought her past screaming to talking. We read to her often. We worked with social interaction. She was able to attend school, excelling in reading and spelling. She attended public school through sixth grade. At that time, we chose to teach her at home, knowing that she could not deal with a huge junior high.

I am a wife and the mother of three children. I was once an active, energetic woman. I was tutoring my children, caring for my family and home, and enjoying activities with friends. I woke up one morning in October of 1987 with what I thought was a terrible case of the flu. Like my sons, I have never recovered. I spend most of my time in bed, getting up for only short periods of time. I am rarely able to prepare a meal for my family. I am often too ill to take a shower or get dressed. On a good day I might get out to lunch with my husband or a friend.

We are considering selling our home, because the stairs in our two story home are becoming increasingly difficult for us to climb. We have made the difficult decision to place our daughter in residential treatment, as I am now too ill to meet her special needs.

My husband is a cost estimating engineer. Along with the demands of his career, he worries about the future of his family. He has been very supportive, but I am concerned about the great deal of stress he is under. He is also a victim of our illness, and wonders when he will have a whole family again.

**I am grateful that our family has pulled together in our crisis. Other patients have not been so fortunate. Some have been deserted by spouses who could not deal with their chronic illness. Many cannot work, and have lost their homes. Friends and family often fall away; out of fear or denial. Too many deal with their illness alone.**

**We have an illness which raises many questions and has no solid answers. We do not know why we are ill, or if we will ever have our lives back again. While we all wait for a cure, the world is losing artists, teachers, writers, musicians, government leaders, doctors, psychologists, and many young people with the same potential.**

**I know many Chronic Fatigue Syndrome patients. Not one of us wants sympathy, but we do need understanding. This can only come from the continued education of the public and the medical community. With the help of the Committee and increased research funding we can dare to hope for a healthy tomorrow.**

**I would like to thank the Committee for your time and efforts on behalf of all CFS patients and their families.**

## STATEMENT OF RAYMOND M. BERGER

Mr. Chairman, I have asked Ms. Sharon Loveless to carry this testimony to your committee. Ms. Loveless is an intrepid and courageous Chronic Fatigue Syndrome patient who has been active in the movement for greater public and governmental undrstanding of this disease.

I was first diagnosed with Chronic Fatigue Syndrome or Chronic Epstein-Barr (as it was called) some four years ago. Since then I have had the opportunity to meet many other individuals with this illness, to read extensively about it and to talk with many physicians and health care professionals interested in the problem.

It is clear from the work of the federal government itself, through the efforts of the Centers of Disease Control and the National Institutes of Health, that Chronic Fatigue Syndrome

(CFS) represents a grave public health problem. This is due to the very debilitating effects of the illness, which often leaves its victims unable to work or even to care for themselves. There are indications that this illness may affect hundreds of thousands of people in our own country, and many more worldwide. (The Centers of Disease Control are now conducting a surveillance study which should provide more data about the incidence and prevalence of this disease, but other studies have shown the syndrome to be familiar to most health care practitioners). Some experts believe that the incidence of CFS is increasing, and that it may affect a great many more victims than AIDS.

Another inescapable conclusion from a reading of the literature in this area, is the link of this disease to other immune disorders such as AIDS, lupus, multiple sclerosis and many forms of cancer. While genetic predisposition is almost certainly implicated in the etiology of this disease, exposure to environmental toxins has emerged as an area of great concern. Since the end of the Second World War, our citizens have been unwitting participants in a grand experiment whose consequences are only beginning to be perceived: we are the first generation of humans to live in the Chemical age. Most of us live in urban areas and experience the ravages of polluted air, water, and food contaminated with pesticide, herbicide and drug residues whose effects on biological systems are poorly understood. Certainly, our federal agencies should be much more activiely involved in the study and monitoring of these sources of pollution and their effetcts upon our world.

This testimony represents just one voice among the many sufferersand their loved ones. Our voices appeal to you as leaders of this nation: please take notice. Please address this very grave threat to our selves, our children and our future. In thinking about where I feel the Congress might best direct its efforts, I have come up with the following list of recommendations:

1. Provide a mandate for increased funding and activity at the federal level to protect our environment. Regulate the introduction of new chemicals and products so that their

environmental impact is known before they are widely introduced into our environment. Control the activities of corporation which pollute or otherwise disregard our environment.

2. Pass legislation, long overdue, that will finally guarantee quality health care to all citizens. As our population ages and as we become sicker due to immune disorders, national health insurance will no longer be a dirty word. Your constituents will insist upon it as a necessity.

3. Provide funding for health care provider and public education about the full range of immune disorders, with particular attention to AIDS and CFIDS. People have a right to know how these illness can be prevented or ameliorated.

4. Increase funding for research into the causes, treatments and cure for immune disorders. When the personal and economic destruction of immune disorders are considered, the current level of research funding is absurd. What will future generation say of our shortsighted funding priorities in the last decade of the twentieth century?

5. Ensure that every citizen disabled with AIDS, CFS and other immune disorders is provided with an economic safety net. The Social Security Administration must continue its efforts to document these diseases as bona-fide reasons for disability payments. Social services must also be provided to help victims lead the most productive and independent lives possible, within the constraint of their disabilities.

Thank you to Ms Loveless for her efforts on behalf of all CFS patients. And thank you Mr. Chairman, for your attention to this most serious matter.

## STATEMENT OF JOHN H. RENNER, M.D.

My name is John H. Renner. I am a family physician, and have been a health educator and consumer advocate for the past 25 years. I am President of the Consumer Health Information Research Institute, Kansas City, Missouri; a clinical professor of Family Medicine at the University of Missouri-Kansas City; and have written a health column for the *Kansas City Star* for the past five years. I am a member of the Board of Directors of the National Council Against Health Fraud, and in March of 1988, I co-chaired the federal Food and Drug Administration's National Conference Against Health Fraud, held in Kansas City.

The Appropriations Bill that this Committee is reviewing regarding Chronic Fatigue Syndrome (CFS) is a vital piece of legislation. It will not only seek to educate health professionals and the general public about Chronic Fatigue Syndrome, thus "demystifying" it; it will also allocate increased federal funding for the research and development of legitimate medical treatments for CFS, which will hopefully lead to an eventual cure.

It is estimated that several thousand Americans have CFS, a potentially debilitating disease which causes extreme fatigue among its other symptoms, and may last for months or years. The symptoms associated with CFS can resemble many other illnesses. Therefore, careful, precise testing is required and for a proper diagnosis, patients should meet specific Centers for Disease Control-developed criteria.

Currently, there is no clear cause or known cure for CFS. This is exactly the type of disease the purveyors of quackery like the most; they are adept at offering easy solutions to such complex problems and providing their false promises of hope and relief. The fatigue associated with this illness can be so debilitating that CFS patients are extremely vulnerable to the pitches of the quack.

Many individuals are being seriously misled in the diagnosis and treatment of this disease by the purveyors of health quackery and misinformation.

Individuals are being led to believe they have CFS when they do not, based on such misused or fraudulent diagnostic procedures as hair analysis, blood and "live cell analysis" tests; and applied kinesiology.

Many CFS patients turn to so-called "alternative therapies" seeking relief from their symptoms. As a physician and consumer advocate, I have received numerous phone calls and letters from CFS patients detailing the treatments they have tried and the products they have been sold.

Some of the fraudulent products I have seen marketed to CFS patients include: the Sunrider Corporation's nutritional supplements which purportedly treat a variety of chronic illnesses; various dental procedures; numerous food supplements from T-cells designed to stimulate the immune system to herbals and other homeopathic remedies; injections of hydrogen peroxide; colonic irrigations; special diets; megadoses of Vitamin C or other vitamins; acupuncture; bee pollen products, and trips to foreign or Mexican clinics which claim to cure CFS.

Not only must CFS patients contend with the physical symptoms of their illness, they must often deal with the discrimination which can result from the ignorance of the general public, and sadly, some members of the health care profession. CFS patients often find it necessary to alter their lifestyles significantly. Many lose their jobs and are denied health insurance, social services, and welfare assistance.

Many are treated as though they are somehow totally mentally ill, even though CFS is a physical illness with psychological components as are all illnesses. The public's misconceptions about CFS are further fueled by pseudo-scientific practitioners who claim that the disease is contagious and can be contracted through such simple means as "minor contact with a person coughing in the elevator or in the aircraft seat next to you, from children who are transient carriers of the virus or from an inconsequential embrace at a reception." These statements only serve to put blame on the victim; to make the CFS patient feel as though he or she engaged in some "preventable behavior" which subsequently resulted in his or her illness.

Only through a program of public awareness and education will CFS be "de-mystified" and the purveyors of health quackery thwarted in their attempts to sell the vulnerable their fraudulent, worthless products.

Based on my experiences as a physician, health educator, and consumer advocate, I encourage this Committee:

o to provide Chronic Fatigue Syndrome patients with adequate social, state, and national medical and social service assistance;

o to provide increased funding for legitimate medical research and treatment development;

o to conduct a vigorous public awareness campaign;

o to provide health care professionals with access to comprehensive CFS knowledge; and

o to ensure that CFS patients can receive continual support and access to accurate, legitimate health information regarding their illness.

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## STATEMENT OF ROSE KRAHE

My daughter after 41 years of good health, in January, 1985 came down with mononucleosis. After several weeks, she returned to work, only to have a relapse and was out for 2 weeks. She then worked part time for 4 months but she got progressively worse. By July 1985, she had fevers all days,sweats, diarrhea, swollen glands, muscle aches and weakness. She could not concentrate for more than a few minutes at a time. She had to stop working and spent most of her time in bed, unable to even look at T.V. for more than 15 or 20 minutes a day. During this time she was diagnosed as having Chronic Fatigue Syndrome. Since she lives alone, many days she would be too weak and foggy minded to make her lunch or dinner and would have to do without. Now, she is well enough most days to make her own meals and take a shower. Before and after each task, she must rest. Trying to vacuum one bedroom has put her in bed for two weeks. After 5 years of trying unsuccessfully numerous therapies, wasting thousands of dollars, she is still unable to work or have a normal life. She must consider moving to a smaller apartment. But where to move? Since her illness she has developed allergies to practically everything. Exposure to a chemical or perfume intensifies symptoms causing increased muscle spasms and weakness and making her mind so foggy, she cannot think.

Her life has become a constant hell of pain and flu-like symptoms. The scary thing is that no one knows the cause and no one knows the prognosis - will she recover or will this go on forever. Reading a book or solving math calculations are impossible.

Prior to becoming ill, she had received a B.S. in Biology in 1966 and an M.B.A. in 1984 and has worked constantly for 19 years. She was active in skiing, aerobics, dancing, politics, a member of the Board of Trustees of her Condominium Assoc., etc. She worked full time as a Section Headfor E.R. Squibb since 1978.

This devastating illness, mostly hits people in their 20's& 30's and can go on endlessly. As a mother it leaves me heartbroken and there is not much I can do and with no cure in sight.

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## STATEMENT OF SHARON LOVELESS

Mr. Chairman - I am presenting this testimony, for the record, regarding the debilitating physical effects and the devastating social impact of a disease, now known as Chronic Fatigue Syndrome (CFS). My name is Sharon Loveless, I am a patient, support group leader, as well as the state director for Chronic Fatigue Syndrome Awareness in the state of California. I have been actively involved in the support network since early 1986, attended 4 national conferences, spent numerous hours absorbing medical journal articles, and even more hours with physicians in attempts to improve, or at the very least, halt the slow deterioration of my functionability, and relieve immobilizing pain. I have heard the stories of hundreds of sufferers, and submit to you that this disease should be addressed as vigorously as any invasion from another country. For this disease is striking as surely as any war on the lives of millions accross the nation. It is, perhaps, worse than a war, when one at least knows the enemy. Lack of substantial funding keeps the researchers from identifying, with certainty the enemy. Without this answer we remain unable to mount a defense and the result has been a growing number of casualties. Our nation is weakened as generations of Americans are struck down in their learning and productive years; as the invader shows no preference for age. The financial drain is staggering at federal and state levels from useless tests; while inadequate funding keeps researchers from a conclusion of the definitive testing that is necessary for a clear diagnosis.

My contact with patients and support group leaders, nationwide, reveals to me that even if the circumstances vary, the theme remains the same; thousands of dollars spent, numerous physicians seen, and too many probing tests, with little, if any, help offered. Many who call me have long ago given up on, or been humiliated out of, traditional medicine. Sadly, there are many professionals in modern medicine who abide by the theory that if they don't recognize the illness, you simply don't have one. The pyramid effect the lack of a national education process has on the CFS sufferer is horrendous socially and financially. Without nation education and adequate funding no test can be developed, no diagnosis given; without a diagnosis one remains ineligible for all assistance needed for a chronically ill person. Health benefits, sick leave, home care, tutors, not to mention the moral support of friends and relatives, are all withheld. At a time when support is needed the most, many are left crippled, to fight the war alone; as marriages deteriorate and friends drift away. It has been documented that the immune system is altered with CFS and medical literature is concise in the effects that stress has on the immune system. At a time when one must take every measure possible to build their immune systems the ignorance at large does nothing but create stress, as patients struggle daily to function, they must fight to merely survive.

I am not unique in my own tale of a career cut short, wrecked marriage and slow decline to below poverty income. Not to mention the once close friends, who have drifted away because illness is boring and too depressing to face. I have lost that person I used to be. I was once a rollerskating enthusiast, I now go on outings in my wheelchair. The drain financially was far more than ever bargained for, as I have been hospitalized on numerous occassions, as the virus invaded my connective tissues, my spinal cord and brain, my lungs, digestive track, and muscles, as well as the mitral valve of my heart. It's course is indeed systemic and it has been random in it's attacks. I am at times an intelligent, concise person, but without notice I have periods of sheer fright, as I become a whimpering frightened child at the loss of my mind. After 17 years in the dental profession, if the pain hadn't of made it intolerable to work, the loss of my memory would have demanded it. I had certainly learned every aspect of the office, like the back of my hand, towards the end I found myself staring into a surgical cabinet, wondering, what the heck had he sent me to get, and what in heavens name did it look like? Too many times, I found myself playing a guessing game, with sheer panic. At 34, could I be senile? Aside from a career I enjoyed, I spent three nights a week and weekends on a football field, as the Girls Co-Ordinator for the Long Beach Football for Youth, Pop Warner program. I now depend more on the children than they do on me, as seizures and sporadic memory loss have made me very leary of being on my own. I am aware many physicians like to believe this disease does not progress, my case and many others who have been ill this length of time, serve to suggest to them that they are still trying to paint too benign a picture of a devastating, debilitating disease.

As a support person, I am a voice of hope, where I, each year feel less and less for my own recovery. I do see hope in winning this battle, if it is recognized swiftly and appropriate measures are taken by Congress and other levels of government. I am not a physician, nor a scientist, so I will leave that input of data to the inquisitive and compassionate few, who have joined us in the trenches. Through my years of decline I have felt great hope, as more and more great minds have joined the war at hand. You can help those great minds, who stand ready, willing, and very capable to seek out and conquer the enemy and end the casualties of young and old Americans. I strongly urge that your support be in the form of a realistic nationwide educational program, and adequate financial support, and that it be instigated with the speed at which you would respond to anything that threatens all citizens of the United States.

Page three is an attachment to my testimony from Rodman Shankle, M.D., a neurologist who has documented the neurological effects of this illness based on the sufferers he treats at his practice at the University of California, Irvine.

Thank you for your time and consideration of my observations, and those of Dr. Shankle.

## STATEMENT OF R. CLAUDETTE FISKIN

Mr. Chairman and members of the Committee, it is for all CFS patients whose physical burdens have been compounded by ultimate poverty, rigid social systems, and unevenhanded distribution of Social Security Disability Benefits, that I feel obligated to advocate for today as I take the opportunity afforded me to tell my multi-family-member CFS story. It is my intent to be informative rather than critical in this presentation. However, at the same time, I hope to clearly relate what it means to be disabled with CFS and poor in 1990, America.

My 12 year old son and I became ill during the Summer of 1986 with an illness that has come to be known in 1990 as Chronic Fatigue Syndrome (CFS), and, to date, we have not fully recovered. This one sentence both summarizes the salient point of our CFS story and heralds the implications of this reality.

Instead of gradually getting better, we became worse at an alarming rate with a staggering number of physical symptoms, unlike anything either of us had ever experienced. According to our physician, my son and I meet the full criteria for CFS as set forth by the Centers for Disease Control (CDC) in March, 1988. The fact that we met this criteria 2 years before it was established points to the fact that an illness without a name is still an illness, and whether or not the patient is recognized as ill, he is still in pain, and he suffers. Ultimately, CFS forced my son out of school, and I had to stop working as a professional Social Worker in private practice. Neither my son nor I have recovered to the 50th percentile of our former functioning. We are in the fourth year of CFS illness, and the progress my son and I have made toward regaining our health has been measured in terms of years instead of weeks or months. All aspects of our lifes have been radically altered, and due to my inability to support my family, we lost our home, most of our possessions, and are now subsisting on $236.00 monthly in the form of a Welfare, AFDC check. Our CFS family story is representative of countless other CFS patient families.

### ADVOCACY FOR CFS PATIENTS IN POVERTY

Whereas CFS can disable the body, the added burdens of poverty can kill the spirit. For far too many CFS patients, it is an out-of-control, sickening, downward spiral to the lowest rung of the poverty ladder, and the journey is routinely frought with frustration, humiliation, and despair.

As a professional Social Worker, I once worked within the network of social systems I have now had to access as a CFS patient, and the first-hand experience which is representative of a significant number of CFS patients has yielded the following sobering facts which clearly define what it means to be poor in 1990, America:

(1) Welfare subsidies do not reflect 1990 cost of living reality. (2) Some states do not have welfare benefit categories for indigents. (3) Waiting lists of years are not uncommon for subsidized housing. (4) Fair-market housing subsidy rates are often less than actual

rent charges. (5) Medicaid does not address testing and medication needs of CFS patients. (6) Many physicians do not accept Medicaid patients. (7) Food Stamp subsidies do not adequately feed a family for a month. (8) The food Commodity program is nearly non-existent in some states. (9) Generally, Legal Aid programs are unprepared to represent CFS patients. (10) Utility supplemental programs do not keep pace with rate increases.

Many CFS patients find themselves needing help from social institutions. Aside from the fact that there is an ever-widening distance between those with resources and those without, the sick and disabled of this disinfranchised group, whose needs have not been met by society's safety net of institutional help, stand an ever-increasing risk of becoming totally invisible in society. In effect, they become "silent statistics".

The one system I had the right to access based on my work record , failed me, along with countless other CFS patients in need of disability benefits. The crux of the problem, therefore, for many CFS patients, is the fact that they are opted out of the social systems designed to help them. Many, as myself, are middle-aged with years of struggle and uncertainty ahead until we can access our own Social Security Retirement Benefits. CFS presents challenging bio-social and bio-political problems that must be addressed at the National policy-making level. To the degree that CFS is recognized and treated as a major public health problem, is the gauge CFS patients can use to measure hope for their future.

## CFS FUNDING RECOMMENDATIONS

Mr. chairman and members of the Committee, as you go through you decision-making process and make your final recommendations, I urge you to give thoughtful consideration for the needs of CFS patients in the coming year. Specifically: (1) increase funding to the Centers for Disease Control for all aspects of their current and ongoing CFS research; (2) increase funding to the National Institutes of Health for their research activities into the cause(s) of CFS; (3) increase funding for independent researchers; (4) earmark funds for physician and health professional education; (5) earmark funds for public education on CFS; (6) designate funds to appropriate agencies for coordinating international information about CFS; (7) designate funding for the establishment of a National Research Center for CFS; (8) earmark funds for each State to aid in the establishment of CFS information and physician referral services.

For the Record, on behalf of CFS patients who must cope with poverty as well as chronic illness, I strongly advocate for more humane and responsive social systems action for those in dire need. Between the Welfare system and the Social Security Disability Benefits system, CFS patients must receive help.

Thank you for entertaining patient reports for the Record during you Committee sessions this year.

## STATEMENT OF JOHN UNDERWOOD

Mr. Chairman - I am submitting this testimony for the Congressional record. My name is John Underwood. I am a journalist in the Los Angeles area reporting on medical and scientific issues for Cal-Net, California Public Radio, and previously National Public Radio, since 1982. It was not until the winter of 1987, however, that I became aware of a silent epidemic striking down millions of Americans across all walks of life. The place was Portland, Oregon. The event was the first official conference on what would be called Chronic Fatigue Syndrome (CFS/CEBV), a disease that comprimises the immune system, subjects it's victims to chronic and often immobilizing pain, and slowly draws the strength out of a life, without actually taking it. Over three hundred such sufferers attended that event, all with strikingly similar stories to tell. All desperate for information and anxious for some kind of action to be taken that might bring relief and hope to their shattered lives. That was two years after the first of many documented outbreaks of a flu-like mononucleosis syndrome that just never goes away. It would be two more years before the Centers for Disease Control would acknowledge CFS and define the syndrome as an organic disease. Since that conference I have filed numerous stories on the heroic efforts of certain physicians, operating independently and without any kind of nationally directed research or clinical backing. These isolated doctors are burdened not only by the lack of good criteria for a clear cut diagnosis and protocol for treatment, but more recently by the shear numbers of patients that overwhelm their normal clinical practices. One such physician I interviewed recently is San Francisco based Carol Jessop whose case load is now a staggering 1,100 CFS patients, and growing. Such numbers of suddenly, chronically ill people coupled with the common factor of apparent immune compromise has not gone unnoticed by a few well known researchers in the field. AIDS expert, Jay Levy, told me CFS will likely be caused by a single virus that activates the immune system inappropriately and then is masked from detection, and in fact, may be the cause of other immune disregulating diseases, such as multiple sclerosis. Another well known immunologist, Sudhir Gupta, of the University of California, Irvine, believes the virus may be a new human herpes virus, activated under certain conditions which triggers this chronic mono-like condition.

For me as a journalist these are all fascinating storylines to pursue. But the story that is most compelling, the one that I have seen and documented over and over, is the personal tragedy of the CFS sufferer. That story is almost always the same; sudden onset of flu-like symptoms, persistent infections of all kinds, all manner of muscle and nerve pain, and, of course, overwhelming fatigue. Some are rendered bedridden, or at least houseridden, but almost all unable to carry on productive work and family lives they had previously known.

I have sat among them at support group meetings, heard their angry and painful words and seen in their eyes the grieving for the loss of who they used to be - teachers, mothers, carpenters, nurses, surfers, bankers, and doctors. A cross section of middle America that, in addition to the tragedy of their personal loss, threatens to cut a wide path through the productive backbone of our society. By even the now conservative estimates of the CDC, upwards of three million americans are afflicted with this syndrome, and growing, without even as yet, answers to such fundamental questions as just how infectious is this disease, and what are the long range oncogenic effects?

It is true that Chronic Fatigue Syndrome does not kill with the devastating speed of an active AIDS virus. Nor, has it touched so many of our lives as cancer has - not yet. The cruelty of this disease, and the danger, lies in the fact that it sows its seeds slowly, insidiously, drawing the life out of a human being, without actually taking that life, or in many cases even displaying outward evidence of terminal illness, as we have come to think of it.

But, I submit to you that a life cut short and rendered helpless by overwhelming fatigue, chronic pain, and a social structure that offers little remedy and less sympathy, is no life at all. I have interviewed and casually spoken with hundreds of such helpless cases. In some of the longer standing CFS sufferers I have seen that helplessness turn to hopelessness, with devastating results, and I am seeing more of them all the time.

And so, as one who has observed objectively and humanistically, what this insidious syndrome is doing to a growing subpopulation of formerly productive Americans, I urge you to take immediate and appropriate action to stem the alarming rise of this "Hidden Epidemic", before the helplessness of the few becomes the hopelessness of many.

# MISCELLANEOUS EDUCATION

## STATEMENT OF THE NATIONAL SCHOOL BOARDS ASSOCIATION

**The National School Boards Association (NSBA), on behalf of the 97,000 local school board members across the country, wishes to submit this statement for the record urging a $5 billion in education spending for Fiscal Year 1991 as well as significant increases for child care and Head Start.** Attached is a breakdown of our recommendations for your consideration.

Recent events in world affairs make it clear that investing generously in education programs will be crucial to the national security of our country as economic strength becomes the new measure of international leadership. A strong educational system is essential to advancing America's leadership among nation's in the 1990's. The primary obstacle to that leadership is the growing number of children and youth at risk of being unable to compete in an international economy that demands well-educated workers.

In recognition of this challenge, the President and the nation's governors have identified and set ambitious national goals for our students and educators to achieve by the year 2000. These goals require a significant federal funding role if they are to be met. In this context, NSBA believes that concerns about deficit reduction should be laid aside when considering increases for education — which amount to a minute fraction of one percent of the federal budget.

NSBA strongly recommends that the Senate Subcommittee on Labor, Health and Human Services, Education, and Related Services Appropriations adopt education as its major funding priority in Fiscal Year 1991 and approve a $5 billion increase. Thank you for your support for America's school children.

### FY 1991 EDUCATION APPROPRIATIONS

NSBA's recommendations call for $2.8 billion in investments in elementary, secondary and vocational education, $2.2 billion in increased aid for college assistance programs, $1 billion for Head Start, and $2 billion for new early childhood and child care legislation.

Breakdown of investments in elementary, secondary, and vocational education:

- **Increase Chapter 1 by $1 Billion Over Inflation.** The program now serves only 55 percent of eligible children. A $1 billion increase would serve an additional one million students increasing the total served to 65 percent.

- **Provide $400 million for Secondary Skills and Dropout Prevention.** These programs expand remedial education services in the secondary schools and allow implementation of innovative programs to prevent school dropouts. Although requested by Secretary Cavazos during budget negotiations with the White House, this amount was not included in the final request.

- **Increase Even Start by $100 Million.** This would fund 500 new projects at $200,000 each in all 50 states. Even Start projects integrate early childhood and adult education needed by disadvantaged parents and their children to assure success in school.

- **Increase handicapped Education by $800 Million Over Inflation.** This program is now funded at a little over $2 billion but pays for just

**seven percent of the excess costs of special education. A $800 million increase would bring the federal share to about 12 percent of the sots to education the 4.6 million handicapped children and youth receiving services.**

- **Increase Math/Science, School Improvement, Vocational and Adult Education, Impact Aid, and Libraries by $500 Million. This increase would provide resources to maintain these programs at current service levels and also allow increases to fund a wide range of innovative school improvement and literacy projects, gifted and talented education, and training teachers for improved math, science, and technology instruction.**

## STATEMENT OF SENATOR JIM EXON

Mr. Chairman and members of the Committee, I am pleased to have this opportunity to present to you my strong and unwavering support for several programs which fall within the jurisdiction of this subcommittee.

First, I would like to address the needs of the Impact Aid program. As you may be aware, I have been a strong supporter of this program for many, many years. Nebraska is somewhat unique in that we incorporate just about all the categories available under the program. We have approximately twelve districts that receive Section 2 payments for federally owned land such as Harlan County Reservoir and Sherman Reservoir. Within Section 3 of the program, Nebraska educates military and civilian students from Offutt Air Force Base which is the SAC Headquarters; Indian students from three tribes, the Winnebago, the Omaha, and the Santee; children residing in low-income housing units; as well as various and scattered "3(b)" students eligible under this program due to federal projects such as the U.S. Meat and Animal Research Center in south central Nebraska.

Impact Aid funding is vital to many of the school districts in my state. Bellevue Public Schools depends on Impact Aid for approximately 35 percent of their operating budget. Macy, Santee, and Winnebago School Districts depend on Impact Aid for over half of their operating budgets. Mr. Chairman, we must fully fund this program. The Impact Aid program provides essential, basic funding to these schools. I want to stress, this is not frivolous "extra" spending. This money finances bottom line items for schools, such as books, teachers' salaries, desks, and equipment. This money does not ensure that these schools have top of the line new equipment every year or the latest in new technology. It does ensure that these schools will remain open and available to educate our children. In many cases, these school districts are operating in old worn out buildings and "getting by" in terms of equipment.

If I may, I would like to relate the situation of one of the other school districts in my state that receives Impact Aid. Papillion-LaVista Public Schools have maintain a relatively constant percent of impaction with respect to the Average Daily Attendance - 36.2 to 38.5 percent impaction. However, their Impact Aid funding, as a percent of total budget has decreased, from 8.5 percent to 4.3 percent. That's a 50 percent decrease. Their cost per pupil has increased from $1,565.23 to $ 2,954.59. That's almost a 100% increase. Although the assistance appropriated under this program has decreased in real terms, the costs of educating children has increased. If we want to stabilize and hopefully improve our educational system in this country, we will not do it by cutting basic, bottom line educational funding.

In the past, the Subcommittee has tried to redirect dollars in this program to those districts that are most in need of the dollars. While I certainly applaud the efforts of the Subcommittee, I submit that changes of that magnitude need to be made by the authorizing committee. I would hope that the subcommittee will refrain from suggesting changes that will eliminate two-thirds of the eligible schools until after the authorizing committee has a chance to closely study and re-evaluate the total program. The funding formula set up in the

1987 reauthorization of this program will work if the program is given full funding.

I also support increased funding for the Impact Aid School Construction program. I believe it goes with out saying that our commitment to this program has been a joke over the last several years. If we are lucky, this fund will finance one or two projects while we have over a hundred on the waiting list. If we want our children to go to school, we have to ensure that they have adequate facilities to go to. We cannot demand our students be the best in the world if they have less than reasonable accommodations.

Mr. Chairman, I would also like to lend my support and encourage increased funding for the State Student Incentive Grant (SSIG) program and the Star Schools program. As you know, the President zeroed out both of these fine programs.

The SSIG program provides one of the best deals as far as student aid goes. This program requires at a minimum a dollar for dollar match from the state. Therefore, the student is receiving at least $2 for every federal dollar invested. What other federal program offers that kind of "bang for the buck." We must also work to shift the student aid balance back towards more grants and less loans, especially for the lower income families. Students today are coming out of school thousands of dollars in debt. They can't afford to be teachers, or social workers, or public servants. We must reverse that trend.

The Star Schools program offers diversified curriculum to our smaller schools, especially those in rural areas. Nebraska belongs to the multi-state SERC Consortium. Because of this association, students in Nebraska have access to Japanese, Russian, Advanced Economics, Probability and Statistics, and

Advance Science Seminars. Teachers have access to AP Economics for Teachers, AP Calculus for Teachers, and some wonderful in-service seminars. Many schools in Nebraska would not be able to offer this kind of curriculum without the assistance of the Star School program. Distance learning is exciting and effective. We must continue this opportunity.

Lastly, Mr. Chairman, I would like to touch on the Community Services Block Grant program. Again, President Bush eliminated all funding for this program. I find that a little ironic in light of his proposal to increase funding for the Head Start program. In Nebraska, many of the Head Start programs are administered through Community Action Agencies, which in turn are funded by the CSBG program. You can throw all the money you want at a program, but if there's no network in place to run the program, the money is not going to do any good.

The Community Services Block Grant funds a variety of programs that, at least in Nebraska, tend to catch those that would otherwise "fall through the cracks" of many of the other social and family assistance programs. Although the economy in the rural areas is beginning to pick up, there are still many families in need of some assistance. The CSBG program has proved to be effective in rural areas and in many cases, the assistance provided does not carry with it the stigma of "welfare". Maintaining dignity is very important to Nebraska's families who, up to now, have always been self sufficient.

As a member of the Armed Services Committee and the Budget Committee, I believe that this is a watershed year for federal funding. I believe that we will have a small "peace dividend", and I support moving some of that money into education and other human resource programs.

These programs are ones that provide basic services to young and old alike. We cannot forsake the more vulnerable individuals of our society by allowing the President's budget recommendations to become law.

Thank you Mr. Chairman and members of the Committee.

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## STATEMENT OF THE NATIONAL MILITARY FAMILY ASSOCIATION

As of January 16, 1990, 565,308 military dependent children were being educated in public schools in the United States and its territories. Of these, 220,609 were "a" students. An "a" student is one whose military parent both lives and works on a federal installation. An additional 344,701 were "b" students. A "b" student is one whose military parent either works or lives on a federal installation. These students place a unique burden on the school district in which they are educated. If their military parent both lives and works on a federal installation, that parent contributes essentially nothing to the local or state tax base. If military parents work on a federal installation and live in the community, they do contribute to the local tax base through real estate taxes. They do not contribute to the tax base through personal property taxes, sales taxes or state income taxes.

A substantial majority of military personnel are enlisted. An Army Staff Sergeant receives approximately $500-600 a month in housing allowance. A house payment or rental payment of this amount could not possibly produce a real estate tax of significant proportion.

Military children place unique demands on schools because of their mobile lifestyle. Frequent moves from one area of the country or world to another often mean the student must change reading or math curriculum. Junior and Senior High students create scheduling nightmares as counselors struggle to match the last school's requirements with the current school's requirements. The children may be facing the absence of the military parent or adjusting to the parent's return. They always arrive having to recover from a move and adjust to a new environment.

In September of 1950 Congress passed PL 81-874 to provide assistance to local school districts educating military children. Congress recognized the unique financial burden these students placed on local education agencies. For twenty years Congress fully funded the Authorization for these schools. Since 1970, despite strong support from the Appropriating Committees, funding has fallen short of Authorization. For over ten years the Administration's Budget requests have consistently ignored the financial impact of "b" students. The Congress has yearly added funding for these "b" students.

The FY 91 Budget request continues to ignore the military "b" student and doesn't reflect the acknowledged 7% education inflation rate for "a" students. The Impact Aid Authorization for FY 91 is $835,000,000. The Administration's Budget request is for $618,854,000.

Calls of concern from NMFA Representatives stationed at military installations around the country about shortfalls in Impact Aid funding have escalated this year. Military families are becoming more politically active, as evidenced by their voting pattern. They are also becoming aware that financial problems at their local schools are not the fault of that school or of the school district. Department of Defense studies show that military families will go to extreme lengths to secure quality education for their children. Military members endure extensive commutes and families absorb exhorbitant housing costs in order to be near good schools. Despite these sacrifices, military families are finding quality education for their children more and more difficult to obtain. They also know that the problems caused by insufficient funding affect the quality of education received by the children of the civilian residents of their community. These same residents are having to pay ever increasing taxes just to keep the doors of the schools open!

The upcoming base closures and realignments as well as the anticipated draw down of the military force will place added burdens on some local school districts. The funding mechanisms in the current Impact Aid law will result in extremely low payments under Section 3 (e). School Districts with a sudden decline in military student enrollment will not be able to meet the payroll, even if Section 3 (e) is funded. Schools that have a surge in enrollments will not be able to financially absorb these students because of the same provisions.

NMFA remains concerned about the shortfall in construction and repair in school districts eligible for 815 funding. As the dollars for the Defense budget shrink so will the ability of the military services to fund projects like the construction of a middle shool for the Douglas School District in South Dakota.

In summary, we note that the military impacted schools are educating the military force of the future. Children of military members are 50% more likely to become military family members than are their civilian peers. The force of the future will be smaller in number and its members will need to be even more flexible and able to carry out more varied missions than those in uniform today. That force must be well educated! Is it fair to expect the residents of the community outside the gates of military installations to pay for this education with ever rising taxes? Who is going to pay when those residents are unable to do so? Should the quality of the education received by children of these residents also suffer?

**NMFA REQUESTS FUNDING OF PL 81-874 AT THE FULL AUTHORIZATION OF $835 MILLION.**

**NMFA SUPPORTS THE BUDGET REQUEST FOR PL 81-815.**

## LETTER FROM THE UNITED STATES CATHOLIC CONFERENCE

April 5, 1990

The Honorable Thomas Harkin, Chairman
Senate Appropriations Subcommittee on
Labor, Health and Human Services,
Education and Related Agencies
United States Senate
Washington, D.C. 20510

Dear Mr. Chairman:

In the name of the Department of Education of the United States Catholic Conference, we are submitting a statement which we sincerely request that you enter into the record of hearings which your Subcommittee recently held on the FY '91 requests for education appropriations.

We urge you and the members of the Subcommittee to provide an FY '91 $40 million dollar appropriation to fund Section 1017(d) (Capital Expenses) of P.L. 100-297, the Augustus F. Hawkins-Robert T. Stafford Elementary and Secondary School Improvement Amendments of 1988. Our statement clearly demonstrates the need for more than $40 million to over come the drastic effects of the Aguilar v. Felton decision on the participation of private school children in the Chapter 1 program.

During reauthorization of the Chapter 1 program in 1988, the Senate Authorizing Committee on Labor and Human Resources believed so strongly that eligible children in private schools should be served that they "recommended an authorization of $50 million in FY '89" for "Capital Expenses". (Senate Report 100-222). This exceeded the House recommended amount by $10 million.

Last year, your Subcommittee recommended a total of $22,000,000 for the Capital Expenses program, an amount which was $2,240,000 more than the administration request and the 1989 appropriation. We sincerely thank you and members of your Committee for this increase. The House, however, provided $30,000,000 last year which was resolved with a Conference agreement for an FY '90 appropriation of $26 million for Capital Expenses finally reduced to $25.7 million.

Even with this increase to $25.7 million, which should restore services to an additional 20,000 eligible nonpublic school students beginning July, 1990, there still will remain more than 40,000 eligible private school students without restored services since 1985. You will recall that following the Felton decision in 1985, private school students' participation in the Chapter 1 program dropped 34 percent, from 185,000 to 123,000 students nationwide. Although participation has gradually increased since then, at the end of the 1987-88 school year, participation had only reached 135,699, still 26 percent less than before Felton.

Therefore, we must again request the assistance of your Subcommittee to meet the stated intent of Congress concerning these Capital Expenses: namely, "to provide sufficient funding to enable needy local educational agencies, to the extent possible, to restore Chapter 1 services for nonpublic school children to their pre-Aguilar levels and quality."

We urge the Senate Appropriations Subcommittee for Labor, HHS, Education and Related Agencies to fund the "Capital Expenses" provision of the Chapter 1 program for FY '91 at $40 million.

Thank you for your generous consideration of our request.

Sincerely,

Sr. Lourdes Sheehan, R.S.M.
Secretary for Education

## STATEMENT OF THE UNITED STATES CATHOLIC CONFERENCE

The United States Catholic Conference, the public policy agency of the nation's Roman Catholic bishops urges that the current hearings and decisions on the 1991 Appropriations Act provide $40 million for the Chapter 1 "capital expense" provision of Section 1017(d) of P.L. 100-297, the Augustus F. Hawkins/Robert T. Stafford Elementary and Secondary School Amendments of 1988. The lingering injurious effects of the 1985 *Aguilar* decision still plague the Chapter 1 program for both public and private school children.

1990 is the twenty-fifth anniversary of the Title 1/Chapter 1 Program. As you probably are aware, for over twenty-five years this program has helped countless millions of educationally disadvantaged children in both public and private schools by providing them with specially designed compensatory educational services. From its beginnings as Title I of the Elementary and Secondary Education Act, the program was designed to help educationally disadvantaged children overcome their learning difficulties, and thereby recognized that some of the children who needed and qualified for help attended Catholic and other private schools.

Since the *Aguilar* decision, private school students' participation in the Chapter 1 program nationwide has decreased 34 percent, from 185,000 to 123,000 students between school year 1984-85 and school year 1985-86. Although participation has since increased, for school year 1987-88 it remained at 135,699, 26 percent fewer than before Aguilar. Participation estimates provided by state education agency officials for school year 1988-89 reflect further increases to 141,000 students. But that level still is 23 percent, or 44,000 students, below the pre-Aguilar level of participation.

In 1988, Congress reauthorized the Chapter 1 program and provided help to local school districts to get this program back on track for private school children. Public Law 100-297, the Augustus F. Hawkins- Robert T. Stafford Elementary and Secondary School Improvement Amendments of 1988, authorized "capital expense" funds to enable school districts to comply both with the Aguilar decision and the provisions of the law calling for equitable participation of private school children. The new statute authorized funds - $40 million for fiscal year 1989 and "such funds as may be necessary" for fiscal years 1990 through 1993 - to pay for increased capital expenditures incurred after Aguilar for noninstructional goods and services used in providing Chapter 1 services to children in private schools. Ultimately, increased capital expense funds will mean that more funds will be available for instructional services for both public and private school children.

In June 1988, the House Appropriations Subcommittee for Labor, Health, and Human Services, Education and Related Agencies recommended an FY'89 appropriation of $30 million for Section 1017(d) the "capital expense" provision of P.L. 100-297. Unfortunately neither the Administration nor this Subcommittee made a recommendation for such funding in FY'89. However, because of the House recommendation an appropriation of $20 million for FY'89 prevailed in the House/Senate Conference. After budget reduction, $19.7 million was allocated to the states for expenditure during the 1989-90 school year. To our delight your Senate Subcommittee recommended an FY'90 appropriation for Chapter 1 "capital expense" funds of $22 million. The House again proposed $30 million. During the House/Senate Conference the total FY'90 Chapter 1 "capital expense" funding was compromised at $25.7 million. This made the total appropriation provided by Congress over the past two years at $45.5 million. However, there is still a great need for continued "capital expense" appropriations to help overcome the deleterious effects of the Aguilar decision on the Chapter 1 program for both public and private school children.

A 1989 GAO Briefing Report to Congressional Committees on the Aguilar v. Felton Decision's Continuing Impact on the Chapter 1 Program supports the need for further "capital expense" funds when it reports that:

> "Forty-six of 52 state Chapter 1 coordinators estimated that school districts have or will incur $105 million in eligible capital expenditures. These 46 states had 81 percent of the private school children in Chapter 1 before Felton.
>
> Six states were unable to provide estimates of expenditures. One was California, which before Felton served approximately 11 percent of the private school students under Chapter 1 nationwide, which presumably will add significantly to the total expenditures. The other five states combined served 8 percent of the private school students before Felton."

In sum, there are 46 states showing the need for $105 million for eligible "capital expenses." There are six states with a total of 19 percent of private school children eligible for Chapter 1 services also in need of "capital expense" funds but are unable at this time to estimate the amount.

The $19.7 million "capital expense" funds which were appropriated for fiscal year 1989 were sufficient enough to cover only 31 percent of the $63 million which states estimated that they would have expended by the end of the 1988-89 school year. The recent $25.7 million appropriated for school year 1990-91 increased the total two year appropriations to $45.5 million, but this is still well below half of the $105 million estimated to be needed by at least 46 states not to mention the six other states which have 19 percent of eligible private school children.

In addition, if the number of eligible private school children waiting to receive Chapter 1 services, as reported in the GAO study, is indeed, 40,000 below the 1984-85 pre-Aguilar level; then, we will continue to need the maximum appropriation of $40 million annually to meet the stated intent of Congress regarding these "capital expense" funds:

> "... to provide sufficient funding to enable local educational agencies, to the extent possible, to restore Chapter 1 services for nonpublic school children to their pre-Aguilar levels and quality."

Attached, Mr. Chairman, is a chart of selected states which illustrates the decline in the participation of private school children in the Chapter 1 program after the Aguilar decision. We wish to point out the gradual increase in the level of participation in some states and the creeping decline of such participation in other states. This illustrates our case and the need for a continuation of "capital expense" funds.

Therefore, we urge all members of this Subcommittee, to approve an appropriation of the $40 million for "capital expenses" as authorized for fiscal year 1991.

NONPUBLIC SCHOOL PARTICIPANTS IN CHAPTER 1
COMPENSATORY EDUCATION SERVICES, BEFORE AND
AFTER THE AGUILAR DECISION

| Selected States | Before Decision (1984-85) | After Decision (1985-86) | (1986-87) | (1987-88) | (1988-89) |
|---|---|---|---|---|---|
| Alaska | 114 | 89 | 273 | 966 | 602 |
| Arkansas | 573 | 75 | 352 | 367 | 593 |
| Arizona | 1,039 | 543 | 400 | 773 | 1,8917 |
| Hawaii | 198 | 48 | 68 | 85 | N/A |
| Idaho | 163 | 82 | 118 | 105 | 388 |
| Iowa | 2,303 | 1,344 | 2,384 | 2,327 | 2,259 |
| Louisiana | 6,016 | 1,706 | 2,709 | 3,503 | 2,381 |
| Maryland | 1,839 | 752 | 2,020 | 2,376 | N/A |
| Mississippi | 1,996 | 617 | 1,687 | 1,784 | N/A |
| Nevada | 113 | 39 | 143 | 77 | 68 |
| New Hampshire | 547 | 411 | 301 | 338 | N/A |

## LABOR, HHS AND EDUCATION APPROPRIATIONS

### NONPUBLIC SCHOOL PARTICIPANTS IN CHAPTER 1 COMPENSATORY EDUCATION SERVICES, BEFORE AND AFTER THE AGUILAR DECISION

| Selected States | Before Decision (1984-85) | After Decision (1985-86) | (1986-87) | (1987-88) | (1988-89) |
|---|---|---|---|---|---|
| New Jersey | 11,962 | 7,364 | 6,819 | 6,367 | N/A |
| New York | 39,663 | 31,520 | 20,319 | 21,071 | N/A |
| North Dakota | 491 | 308 | 315 | 300 | N/A |
| Oklahoma | 358 | 213 | 204 | 170 | 175 |
| Oregon | 620 | 538 | 513 | 218 | 626 |
| Pennsylvania | 21,564 | 17,749 | 13,697 | 16,415 | 16,342 |
| South Carolina | 295 | 97 | 89 | 130 | N/A |
| Texas | 5,022 | 2,883 | 9,472 | 4,183 | N/A |
| Washington | 1,088 | 350 | 668 | 806 | N/A |
| West Virginia | 284 | 147 | 202 | 160 | 147 |

DATA SOURCE: U.S. DEPARTMENT OF EDUCATION

N/A: NOT AVAILABLE

# STATEMENT OF RESEARCH IN ENGLISH ACQUISITION AND DEVELOPMENT, INC.

Mr. Chairman and distinguished members of the committee, my name is Keith Baker, and I am the Director of Research for READ, Research in English Acquisition and Development, an important, non-profit research organization dedicated to an examination of effective methods of teaching English. Through our work, READ strives to develop and improve methods of teaching English to both adults and children, by researching and disseminating scholarly articles on English language acquisition.

Our work enables researchers and educators to conduct open and free inquiry into the full range of teaching methods which schools and teachers may use to promote English language literacy. READ's research is conducted without preconceptions, without favor, and without politically predetermined conclusions. READ is supported by contributions from foundations, corporations, and individuals who wish to improve American education and to develop a more literate citizenry.

As a social science analyst, I have served in various research capacities with the federal government since 1971. In 1980, I joined the Department of Education where I directed program evaluations and policy analysis studies. During this time, I directed over 7 million dollars of research on bilingual education. I have authored numerous articles on education and in 1983, co-authored with Adriana de Kanter, Bilingual Education: A Reappraisal of Federal Policy (Lexington, Massachusetts, Lexington books, 1983). This book is based on a policy review of the U.S. Department of Education's programs for the education of language minority students carried out by the Office of Technical and Analytical Services, Office of Planning, Budget, and Evaluation, in the U.S. Department of Education. Although this book reflects the views of Adriana de Kanter and myself, and not the Department of Education, the review was instrumental in shaping government policy leading to a greater acceptance of

English-based programs for teaching non-English speaking children.

The Baker and de Kanter study is regarded as one of the most comprehensive evaluations of existing literature on transitional bilingual education. Our investigation grew out of a request from the White House Regulatory Analysis and Review Group for an assessment of the effectiveness of Transitional Bilingual Education (TBE). TBE is distinguished from English-based methods of instructing non-English speakers by the use of a student's home language for non-language subject areas.

Mr. Chairman, as I am sure you are aware, in addition to mandating TBE through its civil rights policy, the Education Department has directly funded the development of bilingual education programs. The Bilingual Education Act, passed in 1968 as Title VII of the Elementary and Secondary Education Act, is designed to "build the capacity" of local grantees to maintain programs of bilingual education when federal funding is reduced or no longer available. The act also provides funds for teacher training, development and dissemination of bilingual instructional materials.

Although the focus of our study was an assessment of TBE, we also covered the major studies addressing the effectiveness of English as A Second Language, Structured Immersion, and Submersion (also understood as "doing nothing"). The questions which we addressed: "Does TBE lead to better performance in English?" and "Does TBE lead to better performance in non-language subject areas?" Of the several hundred studies covered by our review, 39 were found to apply to our concerns.

In short, our conclusion was that the literature makes a compelling case that special programs in schools can improve the achievement of language minority children. **However, there is no evidence that any specific program should be either legislated or preferred by the federal government. No consistent evidence supports the effectiveness of TBE.** The only American studies designed to be nationally-representative found negative effects for TBE in English and no effects for math (Danoff et al. 1978). Several studies show either ESL or immersion to be superior to TBE.

Since our review in 1983, a number of other researchers have supported our findings. In 1989, Christine Rossell compared two programs, a bilingual education program and an ESL program, operating within the same school district and found superior results for the ESL program. Rossell found ESL students had higher scores in reading, language and math, in some grades, while students in bilingual education never scored significantly higher than the ESL students. In one of the most recent books on bilingual education, Forked Tongue: The Politics of Bilingual Education, (1990) Basic Books, Dr. Rosalie Porter describes her fifteen years as a bilingual education teacher and director and how she came to the conclusion that bilingual education did not meet the needs of limited English proficient children. In her review, Porter discusses three ESL programs she found superior to TBE.

Unfortunately, after more than a decade, federal policy has emphasized TBE to the virtual exclusion of alternative methods. Although the 1988 reauthorization of the Bilingual Education Act did raise the cap on monies for alternative methods from 4 percent to 25 percent, there remains no empirical evidence to support the continued disproportionate funding of TBE programs.

Mr. Chairman, recognizing this committee's concern to find the most effective form of education for the taxpayer's dollar, READ respectfully recommends that the following questions be directed in special congressional oversight:

-- Who is benefiting from federal Bilingual Education programs?

-- Why is 75 percent of the money appropriated under Part A of the Bilingual Education Act guaranteed to go to only TBE, when research shows other programs to be equally or more effective?

-- Why out of the 158 million dollars appropriated for education of limited English proficient children in 1990 did such a large proportion -- over 27 percent -- never reach the schools, but rather go to training and developing bilingual education teachers and materials, when studies show students derive no particular benefit from either of these activities? Indeed, studies show that certified bilingual education teachers can actually harm a student's development in English.

-- Why is the Department of Education allowed to violate the law by withholding critical outcomes data which by right are public information available under the Freedom of Information Act? In specific I am referring to a longitudinal study conducted by contractor Research Triangle Institute, which compared immersion and other programs for limited English proficient students. These data were compiled over three years ago and would be extremely valuable to independent researchers and education experts.

I have raised just a few of the many problems which are preventing the federal government from effectively educating our non-English speaking students.

The answers to these questions may suggest that the present rigid educational bureaucracy is long on habit, but short on its ability to adopt new strategies to reflect the best current knowledge on the subject. New flexibility will only come through diligent and purposeful congressional oversight.

In closing, I would also note our concern over the recent failure of Office of Bilingual Education and Minority Language Affairs to request annual appropriations under the Refugee Assistance Act. We recommend that funding for Refugee Assistance Act programs be restored -- for the most needy of these immigrant children, the refugees, should not be short-changed.

At a time when Americans are concerned with reducing the deficit, it is more important than ever that we spend our limited money in the way which yields the maximum return on our investment. We have no choice but to invest wisely in the education of our children.

Thank you for the opportunity to present for the committee the views of Research in English Acquisition and Development.

## STATEMENT OF READING IS FUNDAMENTAL, INC.

Reading Is Fundamental (RIF), appreciates the opportunity to offer recommendations on the Inexpensive Book Distribution Program (IBDP), P.L. 100-297, Chapter 2B, Secs. 1561(b)(2) and 1563. RIF operates the program under contract to the Department of Education.

As recent major studies again sound the alarm about the state of reading among American children, we respectfully request Congress to invest additional funds in children's reading through the IBDP.

### NEED AND DEMAND OVERWHELM THE AVAILABLE RESOURCES

In the IBDP the government has a program which implements the key recommendations of all major reading studies of the last decade and which succeeds in getting children to read -- at a remarkably low cost to the taxpayer: only $3.13 per child last year.

Yet, ironically, in the 1980-1990 decade, lack of funds and inflation have steadily eroded the program. Today it reaches 550,000 fewer children then it did in 1980. Moreover, as word of its success has spread, demand for its services has increased. Last year alone, based on requests received, RIF conservatively estimates we could have funded at least 1500 additional programs had funds been available.

Considering the IBDP's achievements in getting children to read, the magnitude of America's literacy problem, and the demand for the program, the IBDP is seriously underfunded. Accordingly, READING IS FUNDAMENTAL RECOMMENDS AN FY'91 APPROPRIATION OF $11 MILLION.

An appropriation of $11 million would permit RIF to reach 2,950,000 children, with 9.4 million books and reading services, almost bringing the program back to its 1980 level of services.

Conversely, an appropriation of $8,914,000, as proposed by the Department of Education, would mean a loss of services to at least 64,000 more children.

An appropriation of $11 million is a small investment to throw a major lifeline to America's youngsters on the rising tide of illiteracy.

## RIF/IBDP: PROVEN, SUCCESSFUL METHODS, ADDRESSING PERSISTENT NATIONAL PROBLEM

This year the government once again issued a dismaying "Reading Report Card," reiterating that America is not making the grade in getting children to read. Secretary Cavazos, as have so many others, placed literacy squarely at the heart of the overall education of our children: "Without solid literacy skills we can never expect to see improvements in math, science, history or geography."

While significant reading advances were achieved among minorities, the overall picture remains bleak:

- Nearly 60% of seventeen-year-olds, soon to graduate, could not read well enough to understand a 12th-grade history text or an editorial in a major newspaper.
- A stunning 95.2% lacked the skills needed to comprehend the kinds of written materials prevalent in business and higher education. And these statistics do not include data about students who have dropped out of school altogether.

It is not the "Report Card's" purpose to offer remedies. Thus it is particularly significant that repeatedly throughout the report the researchers noted that across all age levels the most proficient readers are those who read for fun, read regularly, and have reading matter at home.

This observation echoes the findings of others studies, including the benchmark 1985 "Becoming a Nation of Readers," prepared by a commission of America's leading reading experts, synthesizing 20 years of research on how to improve children's reading. These researchers zeroed in on motivation, the need for children to read for pleasure, to have books in the home, and to have their parents involved -- all components of the RIF/IBDP.

But even before these studies were done, the Congress itself understood the connection between early intervention to engage children in reading books and engaging their minds in learning. In 1976 it created the IBDP with the express purpose of motivating children to read widely, often and well, and to provide them with books to do so. The studies verified what the Congress already knew. And the IBDP has lived up to the expectations of Congress -- and more.

Consistently, through surveys, studies and unsolicited comments from educators, parents, librarians, and even children, the most frequently cited effects of the RIF/IBDP program are:

- Children reading more;
- Increased reading abilities;
- Increased library circulation
- Increased parental involvement;
- Improved attitudes toward reading and learning.

Yet despite these results, the studies' recommendations and the alarming data on inadequate reading skills among youngsters nationwide, the IBDP which IS getting kids to read and IS getting reading matter into the homes is able to reach fewer than 5% of those eligible for its services. Last year our funding permitted us to reach only 2,450,000 children.

Although the IBDP has received some modest recent increases, these have been insufficient to offset rising book costs over the last 10 years, an increase much greater than the general 44.8% inflation rate between 1980 and 1990. One example illustrates the point: the favorite children's classic, E.B. White's Charlotte's Web, almost doubled in price between 1980 and 1990.

Books are, of course, the major cost of the program. Local projects receive NO funds for administration. They receive funds only for books.

## MORE THAN A BOOK PROGRAM

RIF and the IBDP are commonly known as "The Book Program." Of course, the program is getting books into the hands and homes of children, and more important, getting them to read them. And books are the major tools of the program and the incentive which draws communities to the program.

But its dimensions are far greater than the words "Book Program" imply. The IBDP is the foundation of a nationwide movement for children's literacy. It has brought into being an extensive network of innovative, community-based programs spanning all the 50 states, District of Columbia, and U.S. possessions, serving children in 11,694 locations under the umbrella of 3,559 RIF/IBDP projects.

It has drawn 111,205 citizen volunteers from all walks of life into service to get children to read. More than 37% of these are parents of the children served.

The RIF/IBDP network reaches children in schools, of course, where the program is an integral and vital part of reading efforts, and is drawing into schools parents who heretofore had little active role in their children's reading. But unlike many federal education programs, it also reaches into NON-TRADITIONAL SETTINGS where books and reading activities are not readily available and children are at risk.

These include housing projects, migrant labor camps, facilities for teen parents, homeless shelters, preschool centers, juvenile detention centers, and other places where children are out of the mainstream.

For example, RIF/IBDP is reaching youngsters in inner-city community centers in Houston in conjunction with a tutoring program; in a low-income housing project in Fargo, N.D., where older children are teaching younger ones to read; incarcerated young people in Nevada and in a state training school in Eldora, Iowa; migrant farm worker children in Oregon, Florida, Texas, California and other states.

The RIF/IBDP network has also served as a TESTING GROUND FOR INNOVATIVE METHODS to motivate children to read, enabling RIF to develop and disseminate widely the best techniques. It has helped RIF develop a body of knowledge on family reading and has led to some unique parental programs.

For example, a project in Washington state reaches out to teen parents in their own homes to help them improve their reading skills and guide them in bringing up their babies as readers. Similarly, RIF/IBDP is bringing carefully crafted reading services to teen mothers and their children in an alternative school in New Mexico, a housing project in Chicago, and through the Father Flanagan High School in Nebraska.

In Pennsylvania another group of parents out of the mainstream have come together to help their children become readers. Inmates of the Graterford maximum security prison have joined with a volunteer church group to bring RIF/IBDP services to their children on visiting days. The program is partially supported out of the inmates' 13¢-38¢ per hour wages.

Other innovations of the IBDP network involve bringing older children into the service of younger ones, as volunteer fundraisers, readers, and sponsors of RIF projects in New Hampshire, Florida, Ohio, Arizona and Minnesota, among other places.

Similarly, senior citizens, are drawn to RIF's work in various capacities. In Stamford, Vermont, for example, members of a senior citizen club serve as foster grandparents to RIF children, encouraging and rewarding their reading in a variety of ways. And one septuagenarian in Texas has single-handedly raised funds to bring RIF to 17,000 low-income minority children.

The IBDP Network ALSO LEVERAGES PRIVATE SUPPORT, serving as a magnet for widespread family and community involvement and the delivery system for a variety of privately-funded programs. Among the family literacy initiatives spawned by the IBDP and funded with private monies: workshops for parents; family reading rallies; literature (in Spanish and in English) for parents; family reading broadcasts; lending libraries in the workplace; and a nationwide in-home reading competition.

Community-wide initiatives leveraged with IBDP funds, but funded with non-government monies include: three city-wide campaigns in Kentucky, Tennessee and North Carolina to engage the entire citizenry, babies to senior citizens, in programs to get everyone reading; an intensified reading program for all first graders in 15 school districts in 9 states that will reach 100,000 children in the next three years; and a soon-to-be-launched intensive program to reach all fourth graders in the states of Arkansas and Maine.

These are but a few of the initiatives leveraged by the Inexpensive Book Distribution Program. The IBDP is the foundation on which all of these programs and private grants are built.

All of the leveraging was possible because Congress created and continues to fund the IBDP. Without the federal funds, these privately-supported programs would neither have come into being nor continue. All are built on the IBDP and the network it makes possible.

The IBDP is clearly a sound investment that gets children to read and attracts private resources toward that end. LAST YEAR, FOR EVERY $1 OF IBDP FEDERAL FUNDS, RIF AND ITS LOCAL PROJECTS GENERATED $3.03 IN PRIVATE FUNDS, GOODS, AND SERVICES.

## $11 MILLION: A SOUND INVESTMENT TOWARD A CRUCIAL RETURN

The IBDP is a sound, proven, program that succeeds in getting children to read, whether they are in school or in out-of-the-mainstream locations. It is getting families engaged in their children's education. It is developing and disseminating innovative means to achieve literacy among children. It is leveraging private support for literacy programs. It is attracting far more demand for its services than funds now permit RIF to meet.

Above all, it is a major -- and low-cost -- part of the solution to one of the nation's most urgent problems: the need to reverse the downward trend in our children's reading capabilities.

Our children are our first line of defense in the struggle to retain America's preeminence among nations. And literacy is their most powerful tool.

We respectfully urge the Congress to help assure that our children are properly armed by appropriating $11 million for the IBDP for fiscal 1991.

## STATEMENT OF THE CLOSE UP FOUNDATION

Mr. Chairman, Members of this Subcommittee, my name is Stephen A. Janger and I am president of the Close Up Foundation. I am privileged to testify once again to request continued funding for the Allen J. Ellender Fellowship Program, administered by the Close Up Foundation. For the fiscal year 1991, we are respectfully requesting an appropriation of $5.85 million. This funding will allow us to continue to increase both the number and diversity of disadvantaged students and at the same time will enable us to build upon the equally important teacher element of the Ellender Fellowships through teacher training and renewal. Working with all 50 states, District of Columbia, the Commonwealth of Puerto Rico and the U.S. Territories, we propose to establish annual summer and fall Educator Institutes, in Washington, D.C. for 1200-1400 carefully selected educators each year. I will outline this in greater detail later in my testimony.

The Close Up Foundation is a nonprofit, nonpartisan citizenship education organization, whose primary mission is to bring about a more active and informed populace through educational programs in government and citizenship. Over the years, support from the Congress, through the leadership of this Subcommittee, has enabled us to include in our Washington program tens of thousands of economically disadvantaged students and their teachers. This year alone, some 26,000 individuals will participate, several thousand of whom would not have had the opportunity to take part in our Washington Program without the assistance of Ellender Fellowships in conjunction with Close Up generated private sector support.

Let me take a moment to review the progress we have made over the years in meeting our pledge to make the Close Up experience accessible to citizens of all backgrounds, geographic locations, abilities or economic circumstances.

1984: we initiated our Program for Older Americans, to give senior citizens across the country the opportunity to examine firsthand how our government functions and return to their communities with a renewed sense of civic involvement.

1988: we began a Program for New Americans to assist schools in meeting the challenge of the nearly 3 million immigrant children in our public schools. This program gives tenth and eleventh grade students of need who are recent immigrants the chance to learn more about America's cultural and political heritage and how they can help preserve it. Skilled and committed teachers who work with these students also take part in all phases of this program.

All of these programs are designed to instill an awareness of citizenship as an ongoing process, not a one-time experience. Just as learning and education should continue through life, citizen involvement must never be limited by time, age, background or ability.

Mr. Chairman, in requesting funds for these programs, the Foundation, as it has done for almost twenty years, makes a renewed commitment to engage additional sponsors from the private and philanthropic sector, large and small, who share our vision and our urgent concern for the civic education of this nation's citizens. These private sector partnerships are fundamental to all of our program dimensions.

This year, we meet at a time when our country's educational achievements and goals are being scrutinized and reevaluated. Recent studies have sounded danger alarms, warning us that major changes must be made. Most recently, studies conducted by the National Assessment of Education Progress show that students possess only the most superficial knowledge of the basic structure of our government and the contributions of its leaders.

These studies further suggest that our curricula are imparting little more than isolated facts in such fundamental subjects as history and civics. At a time in this rapidly changing world, when so many millions are seeking simply the basic opportunity of self-government it's sadly ironic that young people in the greatest democracy in the world know and appear to be learning little about their own heritage of freedom and self government.

Of all the problems we face in education, the national crisis in teacher preparation is certainly one of the most, if not the most critical. There has been a steady decline in the supply of teachers. In 1992, the number of newly graduated teachers will fill only two-thirds of the positions available. In addition, educators will need to be more knowledgeable than ever before. They will face increasingly diverse populations and teach subjects that are becoming rapidly and measurably more complex. They will be expected to be models for their students and mentors to the younger and less experienced in their profession.

In past year's testimony, I have focused my remarks primarily on students -- about how we have involved students from all 50 states, the District of Columbia, the Commonwealth of Puerto Rico, and the United States territories -- from isolated fishing villages in Alaska and the heart of our inner cities, from remote rural regions and island communities, and from schools located on reservations. I have also talked about the steps Close Up has taken historically to ensure that hearing impaired, visually impaired, orthopedically handicapped, and children with limited English proficiency are mainstreamed into our Washington Program.

But this year I want to talk about teachers - the common denominator of all educational discussion.

For nearly twenty years, the Close Up Foundation has worked directly with teachers from all parts of the country to provide them with experience and resources to nourish their own intellectual growth, self-esteem, and confidence in the classroom. At the end of this academic year, more than 30,000 classroom teachers (along with some 250,000 students) will have come through our Washington Program. Additionally, almost 4,000 educational administrators, including school district and state social studies supervisors, directors of secondary education, district and state superintendents, and school board members have participated in the Washington Close Up experience. These teachers and educational administrators tell us that their participation in Close Up activities has given them a renewed sense of commitment and enthusiasm that enables them to enliven and enrich their classroom instruction, curriculum development and system-wide administration. We also know that these experiences create a huge multiplier effect: teachers reach approximately 125 students each year of their teaching career and administrators have a span of contact and influence almost too broad to calculate over the years.

Mr. Chairman, we believe strongly that any efforts to improve the state of American education and promote active civic involvement must begin with ensuring an ample corps of effective, inspired and well-prepared teachers.

In accordance with this need, the Close Up Foundation is proposing to extend its work with teachers and school administrators through the establishment of Educator Institutes, to be conducted in the summer and fall of each year in Washington, D.C. The principal focus will be newly trained teachers in the fields of civics and social studies and those from school systems with high drop-out rates, teacher turnover, difficulty in recruitment, and concentrations of minority and at-risk students. The institutes would be staffed by experienced Close Up instructors, academicians drawn from appropriate content areas, and by noted educators in the field of citizenship education.

Specifically, we plan five to seven institutes each year for some 1200-1400 educators responsible for teaching and developing social studies and citizenship education at the secondary level. The program would provide educators with an in-depth, first-hand examination of the American political process and the making of public policy, and would take advantage of the unique resources of learning in Washington, D.C. Through the multiplier effect these educators will in turn reach and influence hundreds of thousands of students throughout their teaching careers when they return to their own schools.

An important element of each institute would involve telecommunications, in order to expose educators to the technology of educational television and the use of video materials in the classroom. In the long term, we are interested in developing a series of teleconferences, as we do now with our Washington Program, that would extend the institutes into the school year. This far reaching technological component would be supplemented by partnerships with the private sector.

Like all Close Up programs, these institutes wil be designed to assist educators help students meet the basic goal of participation in democracy more effectively. For only by setting aside textbooks and observing and participating in the workings of government and the making of public policy can educators develop and renew the skills necessary to develop in their students not only habits of the heart but habits of the mind: developing a sense of shared humanity, questioning stereotypes, analyzing the oversimplified, and learning the lessons of costs and compromises, rights and responsibilities. Through such experiences, they can help their students learn through placing information in a human context, and appreciating, rather than taking for granted, the traditions, values, and forces that create a free society.

Let me spend a moment to tell you of a marvelous success story involving the Congress, Close Up and private enterprise. In 1987 the Congress joined with Close Up in recognizing the need to reach out to students in the critical middle school years - grades five through eight. Working together we established the Civic Achievement Award Program (CAAP), in cooperation with the National Association of Elementary and Secondary School Principals. In CAAP's beginning two years it was funded entirely by the Congress and reached 28,000 students. This fiscal year, with the encouragement of both Houses of Congress, Close Up searched for and found an enthusiastic corporate partner, the Burger King Corporation. This year, with Burger King's sponsorship we have been able to reach more than 420,000 students - with 360,000 of those students the direct result of the private partnership. Feedback about the program from students, teachers, principals and parents has been extremely positive. Burger King Corporation has indicated a willingness to assume full sponsorship of CAAP for the future and has pledged an amount for the next academic year that will allow us to reach some 1,600,000 students - an approximate four-fold increase. We could not be more proud of the success of the program, and certainly Congress is to be commended for its vision.

The private sector support will relieve the Congress of continued federal funding (currently $1.033 million) and we would hope that this Subcommittee would see that saving - even from another committee account - as a way to support the nucleus of our educator institute request.

Mr. Chairman, Close Up respectfully requests Allen J. Ellender Fellowship support of $5.85 million for FY91, to be allocated as follows:

o $4.45 million for the basic Washington Program (Parts I and II) conducted for disadvantaged students, their participating teachers, recent immigrants and senior Americans.

- $1.40 million for a series of specially designed civic educator institutes in Washington, D.C. focusing on educators in high percentage secondary school dropout areas, beginning teachers, and administrators whose civics and government curriculum responsibility is significant.

Thank you for your interest in and support of our work and for the courtesy you have extended in permitting me to submit this testimony. I would be happy to respond to any questions you, or other members of this Subcommittee, may have and appreciate your consideration of this request.

## STATEMENT OF THE NATIONAL BOARD FOR PROFESSIONAL TEACHING STANDARDS

Mr. Chairman and members of the Subcommittee, thank you for the opportunity to testify on the need to fund the research and development program of the National Board for Professional Teaching Standards (NBPTS). As teachers, we have first hand knowledge of the urgent need to invest in the quality and future of the teaching force. As members of the NBPTS, we want to thank you, Mr. Chairman, and the members of this committee and the Congress for the confidence you have shown in our mission by enacting $5 million in appropriations for FY 1990 for the research and development work of the Board.

We are here today to ask that you continue your support in the FY 1991 appropriations measure.

Since the Board's testimony before you a year ago, we have made important progress in our efforts to make National Board Certification for teachers a reality by the middle of this decade. The legislation to authorize federal matching funds for the NBPTS was overwhelmingly approved by the Senate earlier this year. The House is moving on that legislation -- hearings have been held -- and we expect committee action in the coming weeks.

The Board is experiencing real success in raising the private research and development dollars which will go to match those federal funds. So far, more than $6.5 million has been pledged from corporations and foundations. In addition, we have a five year, $5 million commitment from Carnegie Corporation of New York to support the Board's operations.

We expect the development of assessments in each of the 34 areas where we plan to develop certificates may take from two to three years from start to finish. We have estimated that it will cost $50 million to set the standards in each field and build compatible high quality assessment processes that command the trust, confidence and respect of teachers and the public they must if National Board Certification is to succeed. At that point, the National Board will become self-supporting by the fees teachers will pay to stand for certification.

While we will proceed to develop the standards and assessment methodologies as rapidly as funding will allow, it is clear to us that if our nation's 2.5 million teaching force is to realize the benefits of National Board Certification this decade, it cannot become a reality without the support of the Federal government and the leveraging of private funds which federal matching funds will occasion. The legislation before the Congress calls for a commitment of $25 million in federal matching funds over a four year period.

### The Mission of the Board

The mission of the National Board for Professional Teaching Standards is to improve student learning in American's schools. Our central goals include: setting high and rigorous standards for what experienced teachers should know and be able to do; developing credible assessments to determine whether a teacher meets those standards; and awarding National Board Certificates to those who do.

National Board Certification will be voluntary. It is designed to complement, not replace, current state licensing procedures. It is designed for experienced, not beginning, teachers. By the end of the decade we anticipate tens of thousands, perhaps hundreds of thousands, of public and private school teachers will have applied for and achieved such status.

It is our expectation that the work of the Board will focus attention on the substantive professional judgment and decision-making that is at the heart of teaching. It will give this nation's best teachers a new and potent reason to stay in the classroom; at the same time, it will attract more highly qualified candidates into the profession, particularly minority applicants. National Board Certification will also help improve teacher education and continuing professional development programs that can foster first-rate teaching. For these reasons, National Board Certification will change significantly the way teachers teach and students learn.

### Assessing Excellence in Teaching

The National Board must develop and implement a comprehensive assessment system that fairly and accurately identifies elementary and secondary school teachers who meet the Board's high and rigorous standards. The assessment procedures must be professionally acceptable, publicly credible, legally defensible, administratively feasible and economically affordable. Furthermore, the assessments must go beyond paper and pencil testing. Procedures must be developed to determine not only what teachers know, but also evaluate what they are able to do. Can they translate complex material into language students understand? Can they exercise sound and principled professional judgement in the face of uncertainty, and can they act effectively on such judgments? Assessments that can recognize the complexity of teaching and reflect the diversity and pluralism of American education must be able to accommodate the possibility that there will often be more than one appropriate approach to convey a particular idea, concept or theory to students, and also accommodate the prospect that as the number and mix of students varies so too might a teacher's practice.

The assessment methodologies and technologies that the Board needs can not readily be taken off-the-shelf. Consequently, the Board will be breaking new ground. It will explore the feasibility of assessment center exercises, of interactive videos, in-depth interviews, portfolios that are defended orally, simulations and on-site classroom observations along with other state-of-the-art ideas.

The Board is committed to attracting minorities to the profession and seeing current minority teachers stand for Board-certification. It will work to ensure that such teachers are well informed about the Board's expectations and processes, about how best to prepare for certification and about the steps the Board has taken and will continue to take to detect and eliminate examination bias and adverse impact. This will include establishing close working relationships with historically Black colleges and universities and other institutions that enroll large numbers of minority students. A central objective here is to ensure that no teacher declines to seek Board-certification out of a concern that the assessment process is unfair.

The Board will not be conducting its research and development activities in-house. Rather, it will direct such funds to teams of scholars and teachers following a process of public notice, open competition and merit review. Not one dollar of federal funds will be targeted to any specific university or other research institution. The Board's research agenda, competitive processes and study designs will be reviewed by both an external Advisory Council made up of leading experts in teaching and related fields and the Secretary of Education, and be open to public comment and scrutiny.

## The Need for Federal Investment

In order to achieve its goal of bringing a comprehensive assessment on-line by 1993, the Board must launch a massive research and development effort designed to accomplish in just a few years what it has taken other smaller and less diverse professions more than 25 years to do. Unlike many professions that offer a single certificate, the Board will be designing a system from scratch that offers over 30 certificates; dramatically multiplying the weight of the task at hand. It will take several years and an estimated $50 million to create a state-of-the-art assessment system. Once this initial start-up investment is made and the Board begins operating the certification system, it will become self-sufficient.

While the overall plan is dependent on the Board drawing support from many quarters, timely federal participation is vital if today's students, who are in need of dramatically improved schooling, are to benefit from National Board Certification.

The federal government is currently spending $11 billion annually on elementary and secondary education and this number is likely to grow. The return on this investment is, first and foremost, dependent on the caliber of the teachers on the front lines of education. Federal support for the Board then, in the form of a modest one-time injection of funds, should pay dividends for many years to come.

Support for the research and development activities of the National Board for Professional Teaching Standards represents a singular opportunity for the Congress to exercise leadership to transform teaching into a true profession. In so doing the Congress will not just be encouraging another small change at the margin, but contributing to the creation of a new institution that will serve as a catalyst for the kind of systemic education improvement the country desperately needs.

### Conclusion

With these benefits in mind, we urge the Committee to provide funding in the 1991 appropriations bill for the National Board for Professional Teaching Standards. We look forward to working with the Committee as you fashion a funding bill that responds to the urgent needs of America's students.

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## STATEMENT OF THE NATIONAL COALITION FOR WOMEN AND GIRLS IN EDUCATION

I am Ellen Vargyas, Chair of the National Coalition for Women and Girls in Education (NCWGE). The coalition represents over 60 diverse women's, education, and civil rights organizations committed to achieving equity for women and girls in all aspects of education. Most recently, NCWGE has been actively involved in the reauthorization of the Carl D. Perkins Vocational Education Act. We are very pleased to have this opportunity to submit our recommendations on fiscal year 1991 funding for federal programs affecting the education of the nation's women and girls.

NCWGE urges you to fund Pell Grants at $6.6 billion, College Work Study at $861 million, Perkins Loans at $448 million, State Student Incentive Grants at $120 million, and Supplemental Opportunity Grants at $579, which would restore funding to FY 1980 levels, adjusting for inflation. During the last ten years, funding for student aid has not kept pace with inflation, despite an increase in the number of disadvantaged students most in need of these important programs. Fully 54% of all undergraduate students are now women, up from 46% only sixteen years ago. A greater proportion of women than men rely on financial assistance for access to postsecondary education. This is probably due to the fact that women students are more likely than men students to be self-supporting, older than average, and from lower-income families. Women are also more likely than men to be single parents.

Funding the Pell Grant program at $6.6 billion will ensure that less than half-time students can get aid without reducing grants for full-time and half-time students. The expansion of eligibility for Pell Grants to less than half-time students particularly benefits women, who are more likely to be studying part-time while they balance work and family responsibilities. NCWGE's recommended funding level will also increase the maximum Pell Grant from $2,300 to $2700, nearly restoring the maximum Pell Grants to 1980 levels in constant dollars. Our proposals for increases for the grant and work study programs will begin to reverse the trend towards increasing reliance on loans rather than grants in student aid packages.

NCWGE recommends funding Special Child Care Services for Disadvantaged College Students (Subpart 8 of Title IV of the Higher Education Act) at $10 million. Because so many women students (and potential students) are parents, the need for affordable and quality child care can often be a barrier to college. In 1986, Special Child Care Services for Disadvantaged College Students was authorized, but Congress has never funded it. Under this program, the Secretary of Education can make grants to colleges and universities to provide special child care services to disadvantaged students. By funding this program, Congress can make higher education accessible for many mothers.

The Coalition also recommends appropriating $75 million for the Office for Civil Rights (OCR), which would restore funding to early 1980s levels, adjusting for inflation. OCR has the important responsibility of enforcing federal laws prohibiting discrimination in education programs or activities funded by the federal government. This includes Title IX of the Education Amendments of 1972, which prohibits sex discrimination in federally funded education programs and activities and which is a key priority of NCWGE.

Funding for OCR has dropped by nearly two-thirds in constant dollars. Not surprisingly the staff size has decreased from more than 1000 full-time staff positions in FY 1980 to the present 802. These cuts have resulted in a dramatic decrease in OCR's ability to investigate complaints, undertake compliance reviews and otherwise carry out its mandate to eliminate federally funded discrimination. The problem is all the more significant in that following the passage of the Civil Rights Restoration Act, OCR's jurisdiction was significantly expanded and the number of complaints and breadth of complaints has increased dramatically. The shrinkage of staff size combined with burgeoning need for compliance reviews and investigation of complaints has shown that OCR has insufficient resources to carry out its mission. In order to bring OCR to a minimally acceptable level of functioning, we recommend the appropriation of $75 million.

NCWGE recommends a $10 million appropriation for the Women's Education Equity Act (WEEA) for FY 1991. WEEA was originally enacted in 1974 to remedy widespread sex discrimination in education. Since then it has been reauthorized four times, most recently in 1988. WEEA authorizes the Department of Education to award grants and contracts to non-profit organizations and educational agencies to develop, demonstrate and disseminate educational equity products and programs. WEEA is extremely cost-effective because models developed can be replicated across the nation. It is the only federal program with a comprehensive mandate to fund projects on equity at all levels of education, for all aspects of education--including administration, athletics, counseling, and curriculum reform--and for both minority and disabled women and girls.

WEEA has consistently been on the cutting edge of emerging issues affecting women and girls in education. WEEA pioneered projects focusing on increasing access for female students to mathematics, science, and computer education, long before these problems were viewed as national priorities. Today, many WEEA projects deal with female dropouts and teen pregnancy prevention.

Over the past ten years, WEEA funding has decreased 87% in constant dollars (In 1980, WEEA funding was $10 million, but today it its only $2.1 million). As a result of these cuts, only 24 projects were funded nationwide in 1990 out of 352 applications. Under current law, funding above $4.5 million can be applied to direct implementation of programs developed with WEEA funds. NCWGE recommends that Congress begin to restore the cuts by appropriating 10 million in FY 1991.

NCWGE requests funding of Training and Advisory Services (Title IV of the Civil Rights Act of 1964) at $46 million. This program provides support to state education agencies and desegregation assistance centers in providing technical assistance and training to districts that are desegregating in the areas of race, sex, or national origin. Funding for this program has decreased from $46 million in FY 1980 to $21.5 million in FY 1990, a decrease of 70% in constant dollars. NCWGE urges you to restore appropriations to $46 million in FY 1991 to help ensure that female students have equal opportunities to learn as do males.

NCWGE recommends $1.5 billion in funding for vocational education for FY 1991. NCWGE is concerned primarily with programs for sex equity and for single parents (including single, pregnant women), homemakers, and displaced homemakers. The Perkins Act provides the largest commitment of federal dollars for educating women and girls in the nation's history, and that commitment has netted results. Nationwide, sex equity funds have successfully established programs to battle sex stereotyping though teacher training, outreach, direct services to individuals or school districts, curriculum development, counseling and development, and research. The number of programs for single parents, homemakers, and displaced homemakers rose from 435 in 1984 to nearly 1000 in 1989.

Most new entrants into the work force in the decades to come will be women, minorities and immigrants. Many will rely on vocational education or on-the-job training for their labor market skills. Over the past decade, federal funding for vocational education has decreased approximately 40 percent in constant dollars. Funding of $1.5 billion for vocational education will restore a decade's worth of cuts and point us in the right direction for meeting the challenges of the future.

Thank you for the opportunity to express the views of NCWGE.

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## STATEMENT OF THE AMERICAN VOCATIONAL ASSOCIATION

My name is Don Bright, President of the American Vocational Association (AVA) and Professor of Vocational Business Education for Bowling Green State University of Ohio.

Supporting funding for the Carl Perkins Vocational Education Act, I appear on behalf of AVA's 45,000 vocational educators and the 16 million students we prepare for work in over 150 occupations.

Today many good things are being observed about vocational education. Recently, CBS Evening News, anchored by Dan Rather, described vocational education as the "classroom of the future." President Bush, last September, pointed to the bright future of our students while noting that 18 of the 20 fastest growing occupations require vocational training. Perhaps the good news about what vocational education can mean to our economy and to our students is finally getting out.

But where Federal leadership is concerned, good news is being confronted by hard facts. A recent Hudson Institute study warns that developing human capital is now every bit as important as developing new technologies, in terms of competing in world markets. Yet, despite growing shortages of trained workers, increasing global competition, and a growing pool of people who will either be tomorrow's "working class" or "underclass", Federal support for vocational education has dramatically dropped. The combined effects of budget cuts and inflation have caused the buying power of today's appropriation to be roughly $300 million dollars less than ten years ago in constant 1980 dollars. Chart I portrays a "Federal Vocational Education Deficit" which is growing.

Federal "underinvestment" is approaching neglect. Vocational education has lagged behind defense spending during the last ten years -- but then so have nearly all domestic programs. Education generally has been underfunded, as Chart 2 illustrates, only during the last few years showing even minimal growth above current services. But there has been no such growth for vocational education and the Federal investment in the education of noncollege graduates continues to trail far behind education as a whole. It is no wonder that the W.T. Grant Commission on Work, Family and Citizenship has labeled our students, America's workers, as the "Forgotten Half".

FY 1991 can be the year to change that. H.R. 7, the House bill to improve and continue the Vocational Education Act, raises authorizations by about 50 percent. S. 1109, the Senate bill, authorizes amounts approaching $1.7 billion, a more than 70 percent increase. Both bills authorize new initiatives and new responsibilities.

But now we must put our appropriations where our authorizations are. Chairman Hawkins of the House Education and Labor Committee has recommended a level of $1.5 billion. AVA believes that is a good place to start.

What do we get for our investment? We get answers for the economy through a workforce that is taught to work, not simply trained for the next job. We get answers for students with special needs, as Fortune Magazine describes, through a "new improved vocational school that acknowledges the vast diversity of its students and offers options suited to their individual needs and learning styles." In short, we get answers for the future.

Marvin Cetron, President of Forecasting International, in his new book, The Great Job Shakeout, lists "winners" in the new job market of the 1990's -- fast-growing jobs, many of them new opportunities spawned by high technology. Two of every three jobs listed as "winners," demanding more than 30 million workers over the next decade, require less than four years of college.

These vocational areas are not dead-end jobs. Our "classroom of the future" prepares students for a new world, one emphasizing robotics, computer assisted manufacturing and design, and telecommunications. But, as Cetron describes, it is also a world where the median income for the occupation of carpenter is more than that of economist; that of bricklayer more than that of actuary; and that of plasterer more than that of political scientist.

Where will the money come from? The American people have some ideas. In an October 1989 Gallup Poll, they were asked: "If you had a say in making the federal budget this year, for the following programs should spending be increased or decreased?" Education was the number one choice for increases. Number one. Greater than combating the drug problem, which was second. More than helping the homeless, which was third. More than space exploration. And more than defense spending, which came in last. But the American people were willing to put their taxes where their wishes were and they were most willing to have their taxes raised to support increases in education.

Congress can give the American people a say in this year's budget. Start with vocational education and close the serious, growing gap in occupational education for American workers. AVA recommends an appropriation of at least $1.5 billion for FY 1991.

Thank you Mr. Chairman. I would be delighted to answer any questions.

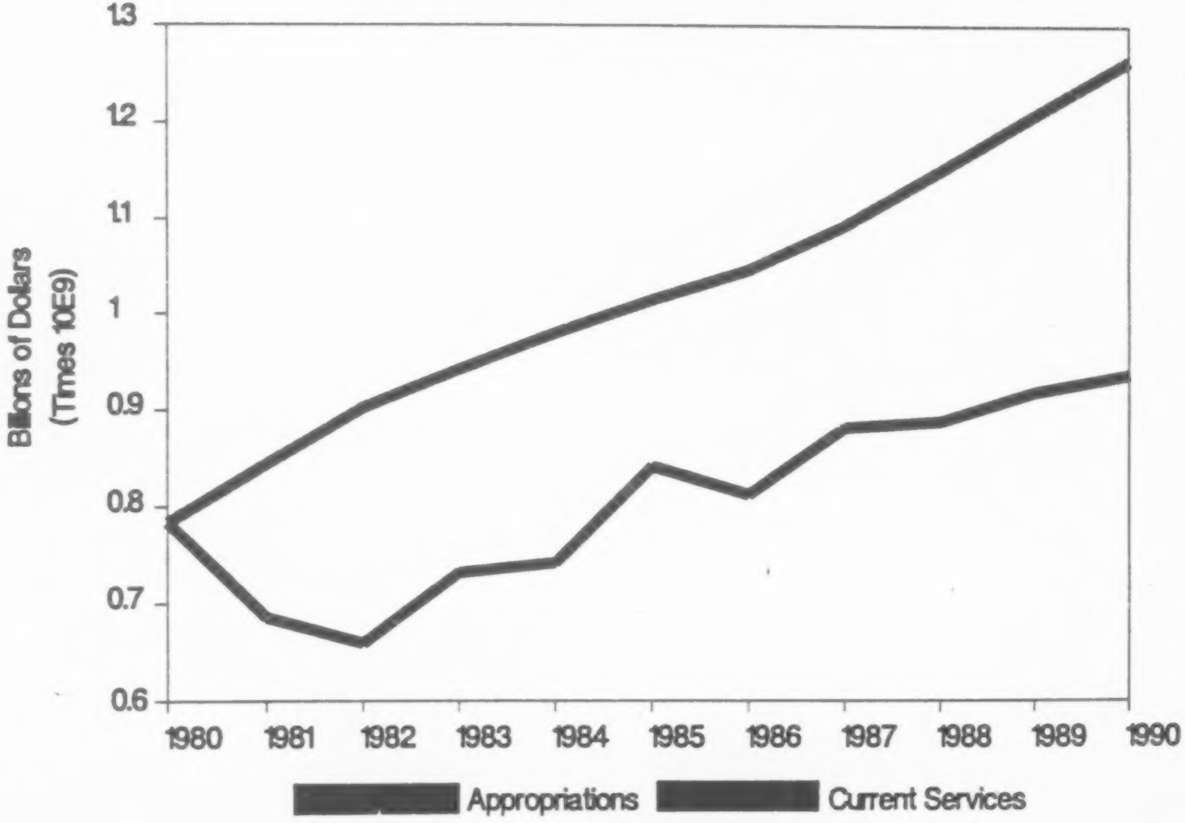
Winners in the New Job Market
Requiring Less Than 4 Years of College
(*The Great Job Shakeout*, Marvin Cetron, pp. 247-253)

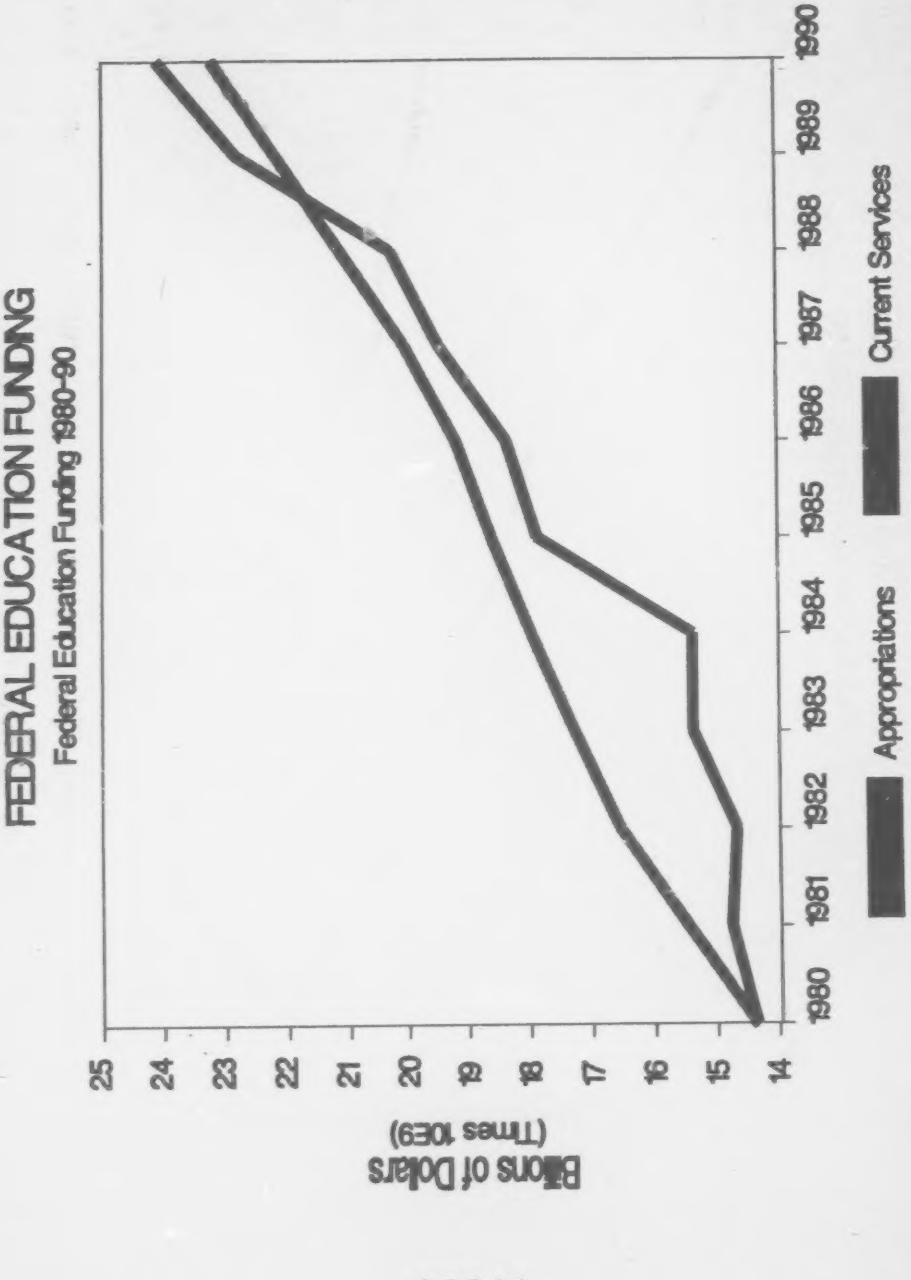
| Job | Needed | Median Income |
|---|---|---|
| Auto Body Repairer | 118,000 | $ 18,000 |
| Auto Mechanic | 638,000 | 16,800 |
| Baker | 77,000 | 20,400 |
| Bank Teller | 336,000 | 14,400 |
| Batter Technician | 25,000 | 16,800 |
| Blue Collar Worker Supervisor | 1,300,000 | 22,800 |
| Bricklayer or Stonemason | 120,000 | 37,200 |
| Broadcast Technician | 17,000 | 26,400 |
| CAD Engineering Software Specialist | 360,000 | 36,000 |
| CAD Info Retrieval Clerk | 300,000 | 14,400 |
| CAD Product Design Technician | 190,000 | 33,600 |
| CAD Product or Systems Inspector | 280,000 | 26,400 |
| CAD Terminal Draftsman | 300,000 | 30,000 |
| CAD Training & Ed Materials Sales | 95,000 | 24,000 |
| CAD Vocational Simulation Instructor | 300,000 | 26,400 |
| CAD Voc Simulation Software Specialist | 150,000 | 22,800 |
| CAG Layout Artist | 40,000 | 21,600 |
| CAG Operations Supervisor | 20,000 | 30,000 |
| CAG Sales Representatives | 30,000 | 36,000 |
| CAG Terminal Input Artist | 40,000 | 21,600 |
| CAM Holographic Inspector | 135,000 | 25,200 |
| CAM Machine & Manufacturing Mechanic | 300,000 | 24,000 |
| CAM Manufacturing Material Controller | 20,000 | 16,800 |
| CAM Production Scheduler | 90,000 | 21,600 |
| CAM Production Superintendent | 90,000 | 30,000 |
| CAM Records Supervisor | 14,000 | 16,800 |
| CAM Special Tooling Design Engineer | 170,000 | 22,800 |
| CAM Technician | 75,000 | 26,400 |
| CAM-CAD Software Coordinator | 80,000 | 30,000 |
| Cable TV Installer | 300,000 | 15,600 |
| Cardiopulmonary Technologist | -- | 30,000 |
| Carpenter | 901,000 | 33,600 |
| Computer Axial Tomography Technologist | 25,000 | 24,000 |
| Computer Console & Equipment Operator | 812,000 | 21,600 |

| | | |
|---|---|---|
| Computer Drafting Technician | 300,000 | 36,000 |
| Computer Graphics Technician | 150,000 | 42,000 |
| Computer Manufacturing Inspector | 250,000 | 38,400 |
| Computer Programmer | 474,000 | 32,400 |
| Computer Service Technician | 93,000 | 33,600 |
| Computer Software Writer | 1,830,000 | 36,000 |
| Computer Systems Analyst | 399,000 | 31,200 |
| Computer Terminal Info Processor | 270,000 | 36,000 |
| Construction Carpenter's Helper | 851,000 | 28,800 |
| Correctional Institution Officer | 169,000 | 30,000 |
| Dental Assistant | 96,000 | 14,400 |
| Dental Lab Technician | 53,000 | 36,000 |
| Diesel Mechanic | -- | 27,600 |
| Drywall Installer & Finisher | 103,000 | 33,600 |
| Electric Power Line & Cable Mechanic | 106,000 | 21,600 |
| Electrical Engineering Technician | 478,000 | 28,800 |
| Electrician | 582,000 | 37,200 |
| Electronic Mail Operations Specialist | 300,000 | 19,200 |
| Emergency Medical Technician | 120,000 | 27,600 |
| Energy Auditor | 150,000 | 19,200 |
| Energy Conservation Technician | 1,500,000 | 31,200 |
| Engineering & Science Technician | 996,000 | 26,400 |
| Engineering Aide | -- | 21,600 |
| Firefighter | 197,000 | 24,000 |
| Food Service Worker (Commercial Cook) | 4,436,000 | 24,000 |
| Hazardous Waste Disposal Technician | 1.500,000 | 33,600 |
| Holographic Inspector | 200,000 | 24,000 |
| Home Electronic Systems Technician | 180,000 | 24,000 |
| Home Rehab Technician | 1,750,000 | 28,800 |
| Illustrator/Commercial Artist | -- | 21,600 |
| Industrial Laser Process Technician | 600,000 | 60,000 |
| Industrial Robot Production Technician | 800,000 | 28,800 |
| Legal Secretary | -- | 21,600 |
| Medical Lab Technician | 205,000 | 25,200 |
| Microcomputer Diagnostician | 200,000 | 42,000 |
| Midwife | 15,000 | 24,000 |
| Nuclear Medical Technician | -- | 21,600 |
| Office Info Center Terminal Operator | 600,000 | 27,600 |
| Office Machine Servicer | -- | 18,000 |
| Painter and Paperhanger | 317,000 | 34,800 |
| Painter, Construction & Maintenance | 469,000 | 28,800 |
| Pest Control Worker | 40,000 | 14,400 |
| Physician Assistant | 51,000 | 26,400 |
| Plasterer | 30,000 | 33,600 |
| Radio & TV Mechanic | 120,000 | 22,800 |
| Receptionist | 490,000 | 14,400 |
| Robot Operations Technician | 75,000 | 26,400 |
| Robot on-the-Job Programmer | 125,000 | 24,000 |
| Robot-Programmed Tool Handler | 75,000 | 21,600 |
| Robot Repairman | 100,000 | 26,400 |
| Secretary or Stenographer | 3,320,000 | 14,400 |
| Security Guard | 548,000 | 21,600 |
| Surgical Technician | -- | 19,200 |
| Telemarketing Computer Programmer | 60,000 | 42,000 |
| Telemarketing Sales Supervisor | 50,000 | 21,600 |
| Telemarketing Specialist | 80,000 | 36,000 |
| Teletext Operations Supervisor | 25,000 | 40,800 |
| Teletext Specialist-CATV Liaison | 30,000 | 45,600 |
| Teletext Specialist-Software Prgrmmer | 30,000 | 36,000 |
| Travel Agent | 52,000 | 21,600 |

FEDERAL VOCATIONAL EDUCATION DEFICIT

Vocational Education Funding 1980-90




FEDERAL EDUCATION FUNDING
Federal Education Funding 1980-90
Billions of Dollars
(Times 10E9)
25
24
23
22
21
20
19
18
17
16
15
14
1980
1981
1982
1983
1984
1985
1986
1987
1988
1989
1990
Appropriations
Current Services

## BUDGET SUMMARY
(in millions of dollars)

| | FY90 | FY91 | H.R. 7 | S. 1109 |
|---|---|---|---|---|
| **FY 91 RESERVE REQUEST** | | $929.8 | | |
| **STATE GRANTS** | | | | |
| Basic Grants | $850.7 | — | $1000.0 | $1500.0 |
| **SPECIAL PROGRAMS** | | | | |
| CBO's | 10.9 | — | 15.0 | 14.0 |
| Consumer/Homemkg | 34.1 | — | 40.0 | 37.0 |
| Adult Trn/Retrn | 0.0 | — | — | — |
| Career Guid/Coun | 0.0 | — | 30.0 | — |
| Industry-Ed Prtnrs | 0.0 | — | 20.0 | — |
| State Councils | 7.9 | — | 8.0 | 10.0 |
| Tech Prep | — | — | 200.0 | — |
| Facilities/Equip | — | — | 100.0 | — |
| **NATIONAL PROGRAMS** | | | | |
| Research | 6.9 | — | (1) | (2) |
| Demos | 11.9 | — | (1) | (2) |
| Data Systems | 4.9 | — | (1) | (2) |
| Bilingual Voc Ed | 3.0 | — | 10.0 | 4.0 |
| **SUPPLEMENTAL** | — | — | — | 100.0 |
| **SMITH-HUGHES** | 7.1 | 7.1 | 7.1 | 7.1 |
| **TOTAL** | $936.7 | $936.7 | $1430.1 | $1672.1 |

(1) 2 % set-aside of Basic State Grant
(2) 2.75 % set-aside of Basic State Grant

## STATEMENT OF THE AMERICAN LIBRARY ASSOCIATION

For the first time in nine years, the Administration has recommended funding for an existing Education Department federal library program, and has even recommended a significant increase for one small library literacy program. The American Library Association, a nonprofit educational organization of more than 50,000 librarians, trustees, educators, and other friends of libraries dedicated to the improvement of library services, welcomes this significant change in policy. However, ALA also notes that the very heart of the largest federal library program, titles I and II of the Library Services and Construction Act, would be eliminated in President Bush's FY 1991 budget. In total, library programs would be reduced by more than 71 percent.

On March 15, 1990, a five-year reauthorization and amendment of LSCA was signed into law by President Bush. PL 101-254 established specific authorization levels for FY 1990 and such sums as necessary for each of the next four years. For FY 1991, ALA recommends appropriations in the amounts newly authorized for each LSCA title for FY 1990. In a similar spirit, ALA recommends for Higher Education Act title II the specific amounts authorized for FY 1987. ALA also recommends amounts shown in the attached table for the Chapter 2 school block grant, the National Commission on Libraries and Information Science, the National Center for Education Statistics, the National Library of Medicine, and the White House Conference on Library and Information Services. ALA emphasizes the clear need for the two programs the Administration would eliminate--LSCA I, Public Library Services, and LSCA II, Public Library Construction and Technology Enhancement.

LSCA began 34 years ago to extend public library service to unserved rural areas, and stands as one of the most remarkable federal success stories in that some form of public library service is now available to almost all the U.S. population. However, neither the need nor the federal achievements stop there, nor should a program which has evolved so dramatically to meet changing needs be judged only on its original purpose. Availability of public library service is not necessarily access if the would-be user is in a wheelchair, does not read English, is confined to an institution, or is blind; or if the library has no access to resources beyond its walls.

Federal funds do not constitute a significant portion of local public libraries' operating budgets. Federal funds do not substitute for state support of public library service, but they stimulate it. LSCA fills in the gaps in public library service, provides seed money for new services and technologies, supports those services more efficiently provided at a regional or statewide level, and stimulates cooperation across geographic and political boundaries. It is a modest, continuing, and entirely appropriate federal role.

How do the states use LSCA I funds to improve public library services? Each state through its library administrative agency receives an allocation and must meet matching requirements. Based on its LSCA plan, developed with widespread input, the state library agency must balance its allocation among subgrants to individual libraries and statewide service delivery. In addition, state agencies may use up to six percent of LSCA I and II funds for LSCA administration (but not more than $60,000). LSCA wisely allows for considerable flexibility for states to tailor programs to their own circumstances within the eligible purposes, but a "typical" state with a few urban areas, a number of small local libraries, and considerable rural area might support the following types of programs.

Subgrants to local public libraries

- Services to the elderly - large-print books, bookmobile service or deposit collections for nursing homes and senior centers
- Literacy services - special materials, tutor recruitment and training
- Services to new immigrant groups
- Services to child care centers - storytelling, library materials
- Urban libraries - which serve many beyond the city limits
- Community information and referral - provide information, create databases of government services, job information
- Small business services - how to compete for government contracts, how to find and use government data, etc.

Statewide services and projects

- Direct service to users not reached by local libraries
    - Bookmobile and books-by-mail service to rural residents
    - Institutional library service to prison inmates, residents of state mental health institutions, group homes
    - Recorded and braille materials, special equipment to the blind and physically handicapped at home
- Support services for local libraries
    - Summer reading program coordination
    - Backup reference service, often through toll-free lines
    - Interlibrary loan services
    - Backup collections and/or centralized cataloging (film and video, foreign language materials, etc.)
    - Consultant support to local public libraries for automation, new technology, literacy programming, problem solving, needs assessment

- Continuing education, training, certification programs for local libraries, especially small libraries with minimally trained staff
- Statewide library card (reimbursement for loans to users outside each library's area)
- Consumer health information delivery

Pennsylvania estimates that the average public library would have to spend another $10,000 to serve blind and physically handicapped users without state and federal aid. State funds help support two regional libraries for the blind, but increases have not kept up with the growth in the visually handicapped as the population ages. LSCA funds have enabled automation of the system, allowing profiles of the interests of these users, so that limited and expensive recorded and braille materials can be used most efficiently.

In addition to targeted population groups such as the blind, LSCA allows funds to be used in more general categories such as improving inadequate service. This provides scarce venture capital for libraries, encouraging new uses of technology and innovative services on a trial basis. If they prove useful, local or state funds may continue them. A growing number of LSCA projects involve library services to children. With all adults working in so many households, libraries have begun taking their storytelling skills and children's materials to preschools and day care centers, and establishing homework centers and special programs for latch-key children. To free scarce local dollars for such efforts is difficult; but with local support, to continue a successful LSCA pilot project is possible. Until the new reauthorization, child-centered activities were not a targeted purpose, but a flexible category such as improving inadequate services allowed states to adapt LSCA to changing circumstances.

What is the impact of such library activities? A recent study in Florida examined the role of public libraries in the educational system (just one of several public library roles). Florida public libraries are open for longer hours and on more days of the week than any other educational enterprise. About 26 percent of the state's population are registered borrowers, the largest enrollment of any educational program. Floridians borrow 47 million books per year on 35 million visits to public libraries. Over one third of these visits are for educationally related purposes. Preschool programs in public libraries reach over 300,000 children. Florida public libraries provide almost one third of the literacy training programs in the state.

For LSCA II, the new reauthorization added "technology enhancement" as an eligible purpose, meaning library bibliographic automation equipment, computer, video, and telecommunications equipment, and equipment necessary to provide access to information in electronic and other formats. This amendment responds to an expressed need, and fits well in the context of current uses of LSCA II library construction and renovation funds. About 50 percent of LSCA II funds are used for remodeling to accommodate the use of new technology, to provide access to the handicapped, and to conserve energy; 25 percent for new construction; and 25 percent for building additions, land purchases, etc.

Public library requests for LSCA II assistance always far outstrip the funds available. Many states award smaller grants to more libraries rather than the full amount requested to a few. The result is that a small amount of federal funds stimulates more than twice the required match for each project. State after state report that most of these projects would not have been initiated without the infusion of LSCA funds.

Federal library programs are among the cost-efficient uses of government money. LSCA and HEA II provide a lot of "bang" for a few bucks. As the Louisiana State Librarian recently said: "This country built interstate highways to make it possible for people and things to move safely, quickly, easily. One highway accommodates everyone, whatever the reason for the trip. In a way, state library agencies use LSCA to build interstate highways for the mind."

ALA appreciates the Subcommittee's support of federal assistance to libraries, and particularly recommends appropriation of the final $1,025,000 for the White House Conference on Library and Information Services. State preconference activity has begun this spring, and financial commitments for the July 1991 Conference must be made. Completion of funding is needed in a fiscal year 1990 supplemental if at all possible; if not, in FY 1991. Both House and Senate members of LSCA authorizing committees, from both sides of the aisle, have indicated on several occasions that they look to the WHCLIS for a major review and policy recommendations for the next LSCA reauthorization.

## SUMMARY OF AMERICAN LIBRARY ASSOCIATION APPROPRIATIONS RECOMMENDATIONS

FY 1991 Labor-HHS-Education Appropriations

| LIBRARY PROGRAMS | | FY89 Appropriation | FY90 Appropriation | FY91 Authorization | FY91 Admin. Request | FY91 ALA Recommendation |
|---|---|---|---|---|---|---|
| Library Services and Construction Act | TOTAL | $127,165,000 | $126,321,000 | such sums | $ 27,737,000 | $207,500,000[1] |
| Title I, Public Library Services | | 81,009,000 | 82,505,000 | such sums | -0- | 100,000,000 |
| II, Public Library Construction | | 22,324,000 | 18,900,000 | such sums | -0- | 55,000,000 |
| III, Interlibrary Cooperation | | 19,102,000 | 19,551,000 | such sums | 20,372,000 | 35,000,000 |
| IV, Indian Libraries | | (funded at 2% setaside of appropriations for LSCA I, II, & III) | | | | |
| V, Foreign Language Materials | | -0- | -0- | such sums | -0- | 1,000,000 |
| VI, Library Literacy | | 4,730,000 | 5,365,000 | such sums | 8,365,000 | 10,000,000 |
| VII, Evaluation and Assessment | | --- | --- | such sums | --- | 500,000 |
| VIII, Library Learning Ctr. Pgms. | | --- | --- | such sums[2] | --- | 6,000,000 |
| Higher Education Act lib. programs | TOTAL | $ 10,035,000 | $ 10,325,000 | such sums | $ 10,325,000 | $ 31,000,000[3] |
| Title II-A, College Library Resources | | -0- | -0- | such sums | -0- | 10,000,000 |
| II-B, Training, Research | | 709,000 | 855,000 | such sums | 855,000 | 5,000,000 |
| II-C, Research Libraries | | 5,675,000 | 5,738,000 | such sums | 5,738,000 | 10,000,000 |
| II-D, Technology | | 3,651,000 | 3,732,000 | such sums | 3,732,000 | 5,000,000 |
| VI, Sec. 607 Foreign Periodicals | | -0- | -0- | such sums | -0- | 1,000,000 |
| Hawkins/Stafford Elementary/Secondary School Improvement Act, ESEA Chapter 2[4] | | $490,740,000 | $487,894,000 | $640,000,000 | $506,620,000 | $506,620,000 |
| National Commission on Libraries and Information Science | | $ 741,000 | $ 750,000 | $ 750,000 | $ 770,000 | $ 770,000 |
| National Center for Education Statistics (incl. library surveys) | | $ 31,122,000 | $ 39,739,000 | such sums | $ 60,404,000 | $ 60,404,000 |
| National Library of Medicine (incl. Medical Library Assistance Act) | | $ 73,731,000 | $ 81,861,000 | such sums | $ 89,916,000 | $121,500,000[5] |
| White House Conference on Library and Information Services | | $ 1,750,000 | $ 3,225,000 | $ 1,025,000[6] | -0- | 1,025,000 |

[1] For LSCA, ALA recommends amounts authorized for FY 1990 in PL 101-254, signed March 15, 1990. (ALA's first priority for LSCA funding is restoration of LSCA I & II levels, zeroed out in the Administration's budget.)

[2] Under PL 101-254, no appropriation may be made for LSCA VIII unless the total for LSCA I, II & III is at least equal to the previous year's total plus 4%.

[3] For HEA II, ALA recommends amounts authorized for FY 1987.

[4] The six targeted uses of Chapter 2 funds include school library resources and training of librarians.

[5] ALA recommends funding above the Administration's request in order to implement the recommendations of the NLM outreach planning panel.

[6] PL 100-382, signed August 8, 1988, authorized a total of $6 million for a WHCLIS, scheduled for July 9-13, 1991.

# VISUAL ARTS AND EDUCATION

## STATEMENT OF DESCRIPTIVE VIDEO SERVICE

> *"It is surely wonderful to have the "blanks" filled in for those of us who cannot see what is going on in the silent and all-music segments of plays, when significant action is taking place. I am totally blind, and have always been discouraged to watch TV, because action pertinent to the plot was visual, and I'd have to ask a friend after the fact. My husband has partial vision, but finds some of the action too quick to follow and that makes it even more frustrating to watch TV. Please continue this wonderful work and expand it if possible."*
>
> \- Marcia and John Kogler
> New York, NY

WGBH seeks federal support for the operation of Descriptive Video Service (DVS), a national initiative to make television accessible to blind and visually impaired people in the United States. Beginning in 1990, this precedent-making program will immediately and directly improve the lives of over 12 million blind and visually impaired people in our country, over half of whom are 65 years of age or older.

The Education of the Handicapped Act (Section 652) authorizes video description services. At a funding level of $1 million per year WGBH can provide a meaningful service of 6-8 hours of programming per week broadcast over the SAP channel of stereo broadcasting and can explore many alternative distribution mechanisms for cable and home video. WGBH requests that the Subcommittee on Appropriations for Labor, Health and Human Services, Education and Related Agencies fund descriptive video for FY 91 at $1 million.

Although the FY90 funds have not yet been obligated by the Department of Education through the Media and Captioning Films discretionary grant programs, WGBH urges the committee to earmark the sum of $1 million for FY 91 in order to expand DVS and the work already done.

Access *is the pivotal issue* of the 1990s in the disabled community, and DVS provides access for visually impaired Americans to the world's primary medium of mass communication. Over 98% of all U.S. homes have television sets playing an average of seven hours daily. While blind people watch as much television as sighted people, they experience extreme frustration at not knowing what is happening on the TV screen. DVS will help blind people gain independence, information and socialization skills, and share in the culture of our society.

DVS is part of WGBH's longstanding commitment to utilize new technologies to reach audiences traditionally underserved by television. With a twenty year legacy of pioneering and perfecting captioning on television for hearing impaired viewers, WGBH has now originated a landmark initiative to make television accessible to blind people. With support from the Corporation for Public Broadcasting, WGBH has been developing and testing DVS since 1985. Viewer feedback confirms that DVS fills an urgent and essential need for described programs. DVS is recognized as an important new service in the blindness field by the American Foundation for the Blind, the National Federation of the Blind and the American Council of the Blind, and many other blindness organizations across the country.

DVS made its debut as a national service on PBS in January, 1990 with the season premiere of AMERICAN PLAYHOUSE. This new service provides narrative descriptions of a television program's key visual elements without interfering with the program's audio or dialogue. The narrated track describes actions, setting, scene changes, costumes, and body language via the SAP (Separate Audio Program) channel, a standard feature of stereo televisions and VCRs. In March, DVS was added to the highly acclaimed series MYSTERY! This series was chosen as a direct result of the audience preference for mysteries as one of the most difficult program types for a visually impaired viewer to enjoy. In April, DVS was added to the PBS series DEGRASSI HIGH.

DVS must be expanded beyond drama to science and nature programs as well as documentaries. Federal support at this critical time will enable descriptive video to operate at a meaningful level and give blind viewers a wide choice of programs *and program types* to watch. DVS can also be applied to home video and cable and must quickly expand beyond its modest beginning on PBS, currently providing 3 hours of described programs per week.

> *"Most of the drama I enjoy is on television. While I can see that something is on the screen, if it weren't for DVS, I could only use my imagination to fill in the silence. With this splendid descriptive narration, I fell as if I am "seeing" the picture myself. I cannot thank you enough for the wonderful service, and I trust that science and nature programs will be added to the list of future DVS program planning."*
>
> \- Phyllis B. Zoebler
> Brooklyn, New York

The 1984 U.S. Census documents 12.8 million Americans with vision so severely impaired that they are unable to read even with glasses. While vision impairment afflicts people in every segment of our population, it is an increasingly serious problem for elderly people. According to the Association for the Education and Rehabilitation of the Blind (AER), 20% of Americans over age 60 have severe vision impairments. The AER also reports that because ours is an aging society, visual impairments among people over 65 will double by the year 2000.

Mobility is a major problem for visually impaired people. Blindness or impaired vision severely limits one's ability to venture out to enjoy cultural and arts programs or social and educational functions. Visually impaired people look increasingly to television to fill a large gap in their lives, but they experience intense frustration at not knowing what is happening on the TV screen. They miss key information (actions, gestures, scene changes, body language) vital to the understanding and enjoyment of the program. Those who live alone feel isolated from this personal medium that shares their living rooms, and those who live with sighted persons cannot participate with their friends and family in the major form of relaxation, entertainment and education the others enjoy. They feel left out because they cannot understand or discuss television programming on an equal level.

Descriptive video can help blind people of all ages reduce the frustrations of daily life and share in television viewing with others. Most importantly, described TV will contribute to the independence of blind and visually impaired people, allowing them to rely less frequently on sighted friends and relatives who, even when they have the time and inclination, may not have the skills to describe what is happening on TV.

> *"I was delighted to hear DVS. It seems like something too good to be true...I realized then how much I was missing. My husband does a good job on the grosser aspects of the action, but he's nowhere as good as your narrator. He doesn't bother with facial expressions, colors, or any attempt to add to the mood of the scene. I am excited by the possibilities."*
>
> \- Dana Walker (Montgomery, Alabama)

Why should blind people have full access to television? The answer is simple. Because everyone else does. Television is the world's primary medium of mass communication. It is an inevitable part of our society and our culture. An astounding 98% of all American homes have television sets--and for seven hours a day the average household has the TV playing. According to the American Foundation for the Blind, visually impaired people watch as much television as sighted people.

The audience response to the DVS launch has been overwhelming:

> *"A word of praise and appreciation for the new treatment of AMERICAN PLAYHOUSE. My wife is legally blind, cannot read subtitles, but does see some form on TV. The voice over, via the SAP channel greatly enhances her understanding and enjoyment of the action. At the same time, I found the voice hardly intrusive, so that my enjoyment was not diminished. This is a terrific use of the SAP channel, and we hope that more programming can take advantage of it."*
>
> \- Bill and Betty Lou Long
> Falmouth, Massachusetts

## STATEMENT OF THE CHILDREN'S TELEVISION WORKSHOP

Thank you for this opportunity to submit testimony on behalf of strong financial support for public television. Specifically, I ask you to support the fully authorized level of funding for the Corporation for Public Broadcasting. I also urge you to direct the Department of Education to commit more funds for national educational television programming that addresses our country's concern for better education.

Children's Television Workshop is a multimedia educational institution whose mission is to use mass communications to educate young people, mostly outside the classroom, but in school as well. To that end, we produce educational television programming that appeals to and attracts children. That programming includes SESAME STREET, our flagship series, which to date has prepared over 40 million preschoolers for the classroom; 3-2-1 CONTACT, our science series for eight to twelve-year olds, and SQUARE ONE TV, our mathematics series for children eight to twelve. None of these three series would exist without the support of the Corporation for Public Broadcasting, and of the Department of Education or its predecessor agencies.

CTW's programs emphasize informal education. The education crisis facing America is so overwhelming that if we want to improve the way our children learn, we cannot rely on schools alone, or on parents. We must use every tool at our disposal to reach children. Since American youngsters typically watch television over 23 hours a week, spending more time in front of the family set than they do in school, converting some of that time into educational programming can significantly increase children's opportunities to learn--can, in effect, extend their school day.

Quality educational television works. Children--regardless of their own socioeconomic background and level of achievement in school--watch our series and learn from them. Here is some of the evidence: a recent nationwide survey conducted by the Yankelovich organization on viewing by preschoolers living in poverty, whether African-American, Latino, or white, confirmed that SESAME STREET is reaching children who need the series most. 92 percent of the preschool children nationwide are current viewers, and nearly two out of three watch the series almost every day.

Studies of 3-2-1 CONTACT have found that after watching the series, 50 percent of viewers engage in some science-related activity, such as reading about a scientific subject or trying an experiment. And most recently, the results of an important new evaluation of SQUARE ONE TV has found that children who viewed the series in a sustained manner showed significant improvement in their ability to solve unfamiliar, complex mathematical problems. Moreover, these improvements occurred regardless of the children's socio-economic background, ethnicity, or gender.

Anecdotal evidence lends further support to these studies' conclusions. To cite just one example, ten year-old Heather Falk, a fourth grader in Davenport, Iowa, wrote to say that she rushes home from school "to watch SQUARE ONE TV almost every day." She adds that in math class at school, she already knew about multiplication, division, and percentages because of SQUARE ONE TV. As a result of watching the series, she says, she feels more confident at test time.

Funding from the Corporation for Public Broadcasting is crucial to CTW's educational efforts in two ways. First, direct funding from CPB helps support SQUARE ONE TV and 3-2-1 CONTACT. Second, through Community Service Grants, CPB also enables local public television stations to pay about one-third of the yearly cost of SESAME STREET, with CTW financing the remaining two-thirds from its own self-support activities.

Children's programming provides about one-third of public television's total audience. It is a unique service of public television; educational programming on a national scale does not and will not exist in commercial television distribution systems. We need more educational programming on more subjects if we are to use technology effectively to help improve education in this country.

Hence, it is my hope that the evolving arrangements among the Public Broadcasting Service and CPB will continue and expand the priority status of children's programming and education. The new plan segregates funding for "independent producers" and minorities. Such segregation should not be necessary for children's educational programming, and won't be, if public television stations, PBS, and CPB make children's education central to their programming.

Funding from the Department of Education is equally vital to the survival of educational children's programming. From SESAME STREET's inception until 1982, the Department of Education or its predecessors invested $30 million in the series. That means that the federal government's total tuition bill has been less than 75 cents per young graduate. The Department of Education's contributions also helped us to produce 3-2-1 CONTACT and SQUARE ONE TV, and to attract additional underwriting from private funders.

We believe that the time has come for the Department of Education to demonstrate once again the kind of bold vision and leadership it exercised in its early support of SESAME STREET--this time to tackle illiteracy. Given the proven efficacy and cost effectiveness of educational programming, I ask you to urge the Department of Education to place CTW's Reading and Writing Project at the top of its funding agenda. Our Project will use television, other media, and extensive outreach to help children aged six to nine to learn to read with understanding and write with coherence. It will not be possible for CTW to tackle this new undertaking without the support of the Department of Education.

In the more than twenty years that we at CTW have been helping children learn, we have proven that television--so often condemned as the enemy of education--is an invaluable ally. Quality educational programming is a tool that should be used to achieve our education goals, because it can reach every American, regardless of race or resources. Public television is the only reliable source of this kind of programming for children. Please support full funding for the Corporation for Public Broadcasting and the Department of Education, and direct the Department of Education to provide more financial resources and extended support to quality educational television. Thank you.

## STATEMENT OF THE NATIONAL ASSEMBLY FOR VISUAL ARTS EDUCATION

Good morning and thank you for the opportunity to address the Subcommittee. My name is David Rhodes and I come before you today to speak for the future of art and design in America. I am the current chairman of the National Assembly for Visual Arts Education, an arts advocacy consortium formed by several like-minded college presidents. I am also president of the School of Visual Arts in New York City, our nation's largest college of art and design.

I'm here to call your attention to the absence of art programs in the proposed Department of Education budget for Fiscal Year 1991. I personally represent more than 7000 undergraduate and graduate art students and all of their concerns but, due to time constraints, I will limit myself to two essential areas that this budget neglects: federal support for basic arts programs in the kindergarten through 12th grade curriculum and graduate study in art and design disciplines.

Unfortunately, the proposed federal education budget is far more limited than even these modest remarks. In fact, while the budget pays lip service to "the arts", actual art and design are not mentioned, in letter or in spirit, in the 87 pages of the document. This by now traditional visionlessness comprises nothing less than a continuing tragedy for America's schoolchildren, a denial of fundamental educational rights, and a dangerous oversight in planning America's future.

As usual, the budget specifies several curricular areas with precision, but the visual arts are completely ignored. For example, the language describing the $213 million Magnet Schools program, fails to include the visual arts, source of some of the oldest and most successful magnet programs nationally. Please understand that art has little hope of generating significant local support and funding unless and until the Department of Education sets a new national example. There is little argument concerning the impact and importance of art in elementary and secondary education. Around the nation arts magnet schools are achieving remarkable results across the curriculum and art-based activities have proven especially effective in reaching children at risk.

Critical support from the Department of Education is required now to help put new art teachers in classrooms and to develop and bring new initiatives to fruition.

Concerning support for graduate and advanced professional study, I would remind you that design is a crucial component of America's international competitiveness. As you know, most of the staples and principles of 20th century design have come to us directly from one art school. The Bauhaus, of course, was not an American institution. We simply inherited many of the aesthetic and economic benefits when Hitler closed the school and the faculty fled here. Such a design windfall will not reoccur. If the 21st century is going to be made in America it must be designed in America. As a first step, postgraduate art and design studies must be specifically included in this budget's graduate fellowships and support programs. Your foresight, evidenced by direct support for graduate study in art and design, can make a difference.

Finally, by failing to recognize art as a fundamental discipline, by denying art to America's schoolchildren, we diminish both their education and our collective future. This is plainly what has happened and what the Department's proposed budget continues. I urge you to reconsider and redress this unfortunate position, and I offer our considerable resources to this end. Thank you.

## UNIVERSITIES, COLLEGES, ET CETERA

## STATEMENT OF THE ASSOCIATION OF AMERICAN UNIVERSITIES AND THE ASSOCIATION OF GRADUATE SCHOOLS

Under current trends, the United States will soon be confronted with a shortage of Ph.D.s that will affect all fields and all graduate education markets--industry, government, and colleges and universities. Prompt action must be taken by all practitioners and patrons of graduate education to reduce the shortage. The Department of Education has a key role to play in that effort.

Fellowships and traineeships are a *proven* means to attract talented students into graduate programs, increase retention rates, and reduce time-to-degree. The Department of Education currently administers programs that address each of the factors generating a divergence of supply and demand in graduate education: the two-decade decline in the number of U.S. citizens earning Ph.D.s; the continued underrepresentation of minorities and women; the sharp increase in demand for new faculty, particularly in the humanities and social sciences; and the increased demand for natural science and engineering Ph.D.s in government and industrial sectors as well as the academic sector.

The Department administers the major federal program supporting research and graduate training in international studies, providing the knowledge and personnel essential to our capacity to understand and compete in a world that is changing at an extraordinary rate. In addition, the Department provides important support for research libraries, which are the nation's shared information resource centers supporting research and graduate education in all disciplines.

Appropriations for the following Department of Education programs will play an important role the effort to increase the supply of U.S. Ph.D.s and help prevent a costly divergence of supply and demand in U.S. doctorates:

*Grants to Institutions to Encourage Minority Participation in Graduate Education (Title IX-A)* provides minority undergraduate students with summer research internships.

*Patricia Roberts Harris Graduate Fellowships (Title IX-B)* support students underrepresented in graduate and professional education.

*Patricia Roberts Harris Public Service Fellowships (Title IX-B)* provide incentives for students to pursue graduate study leading to careers in public service.

*Jacob K. Javits Fellows Program (Title IX-C)* provides fellowships to attract exceptionally talented students into graduate programs in the arts, humanities, and social sciences.

*Graduate Assistance in Areas of National Need (Title IX-D)* supports training grants for study in selected fields of science, engineering, and other critical areas.

*International Education (Title VI) and Fulbright-Hays* programs provide the major federal support for teaching and research in foreign languages, area, and international studies.

*Academic Library and Information Technology Enhancement* programs *(Title II)* assist research libraries to meet the rapidly growing demand for information collection, storage, and retrieval.

## FY 1991 APPROPRIATIONS REQUEST

| | FY 1990 | FY 1991 Administration Request | FY 1991 Higher Education Request |
|---|---|---|---|
| Minority Undergraduate Internships (Title IX-A) | $ 3.5M | $ 6.1M | $ 6.1M |
| Harris Graduate Fellowships (Title IX-B) | 16.0M | 17.8M | 22.0M |
| Harris Public Service Fellowships (Title IX-B) | 3.3M | 1.2M | 3.3M |
| Javits Fellowships (Title IX-C) | 7.9M | 5.4M | 9.4M |
| National Need Training Grants (Title IX-D) | 15.8M | 25.5M | 25.5M |
| International Studies (Title VI), Fulbright-Hays | 39.8M | 39.8M | 50.0M |
| Research Libraries (Title II-B) | 0.709M | 0 | 2.0M |
| (Title II-C) | 5.7M | 5.7M | 10.0M |
| (Title II-D) | 3.6M | 0 | 5.0M |

## THE PROBLEM: THE CAUSES AND CONSEQUENCES OF THE PH.D. SHORTAGE

Graduate education produces the teachers, scientists, and scholars responsible for the discovery and dissemination of new knowledge, the preservation and interpretation of our intellectual and cultural heritage, and an understanding of the broader multicultural environment of which we are a part.

- The U.S. invested $132 billion in R&D in FY'89. Graduate programs produce the future scientific workforce. Graduate students are a key ingredient of *current* research, providing much of the creativity and productivity of U.S. academic research.

- Thirteen and one-half million students attend U.S. colleges and universities. These institutions employ more than 700 faculty. Virtually all of these faculty hold graduate degrees; two-thirds of the faculty at 4-year colleges and universities hold doctorates.

- The Ph.D. market extends far beyond academia. Seventy percent of 1987 engineering Ph.D.s had employment commitments in nonacademic sectors–53% in industry, 17% in government and other nonacademic markets. Fifty percent of 1987 doctorate recipients in the physical sciences had commitments in industry, 15% in government and other nonacademic sectors. Across all fields, 50% of 1987 doctorate recipients had employment commitments outside academia.

Supply and demand are moving in opposite directions in graduate education. Absent countervailing intervention, demand will soon outstrip supply to such an extent that the resultant competition among colleges and universities, government, and industry will exact severe costs to the nation no matter who wins.

- The combination of faculty retirements with other avenues of departure will produce strong, sustained replacement demands over the next 25 years. Beginning in the mid-'90s, increased enrollments will be superimposed on replacement demand to increase sharply the need for new faculty.

- Over the next two decades, the demand for new Ph.D. positions in industry is projected to increase from 3,600 to 7,400. Yet, as with college faculty, a growing demand for new positions will be superimposed on a substantial replacement demand produced by an aging population of scientists and engineers. By 1987, over half of all doctoral scientists and engineers were 45 years of age or older, compared to about two-fifths in 1977.

- Dramatic changes are occurring in the world at a pace that challenges our ability even to catalog them, let alone understand them; both our economic competitiveness and our national security will become increasingly dependent upon our capacity to use the languages of other nations and to understand their customs and cultures.

- The proportion of U.S. citizens earning Ph.D.s in U.S. universities has declined since the early '60s, and the actual number of U.S. citizens earning Ph.D.s has dropped since the early '70s. In 1972, 83% of doctorates awarded by U.S. universities went to U.S. citizens; by 1987, that percentage had dropped to less than 71%. In the physical sciences, the percentage of U.S. citizens earning Ph.D.s dropped from 79% in 1972 to 61% in 1987; in engineering, the drop was from 66% to 42%.

- Non-Asian minorities and women remain severely underrepresented in doctoral education. In 1987, blacks earned 3.4% of Ph.D.s awarded to U.S. citizens, yet they make up 12% of the population. Hispanics, who make up 6.5% of the population, received 2.8% of Ph.D.s. Although the number of female doctorates increased substantially over the last decade to 35% of total Ph.D.s in 1987, only 6.5% of engineering Ph.D.s went to women.

- Current trends in all Ph.D. markets–academic, industrial, and government–will result in an *annual* shortfall of 7,500 natural science and engineering Ph.D.s just a few years into the next century. By the 1997-2002 time period, there will be only eight candidates for every ten faculty vacancies *across all arts and sciences disciplines*; in the humanities and social sciences, only seven candidates will be available for every ten faculty vacancies.

When the U.S. preeminence in science and technology was challenged in 1957 by the launching of Sputnik, the federal government responded with sharply increased funding for graduate education and research. The response succeeded, increasing both the size and the quality of university research and graduate education programs.

Following that buildup, the federal government cut back its support of graduate education sharply. In 1969, the federal government funded 60,000 fellowships and traineeships; today it funds less than 13,000.

Providing the requested funding levels for the programs listed above will provide the Department of Education with the resources to help meet the growing demand for students with graduate training. Each of these programs is described in the following pages.

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## STATEMENT OF THE NATIONAL ASSOCIATION OF INDEPENDENT COLLEGES AND UNIVERSITIES

The National Association of Independent Colleges and Universities (NAICU) appreciates this opportunity to submit comments to the Subcommittee on Fiscal Year (FY) 1991 appropriations. NAICU represents approximately 850 independent colleges and universities, including major research institutions, religiously-affiliated schools, liberal arts colleges, historically black colleges and universities, two-year junior colleges, and specialized colleges of various types.

NAICU is requesting significant increases in a number of student financial assistance programs. We believe these increases are justified despite the fact that there are numerous concerns about the current structure and functioning of the programs. Federal student financial assistance is absolutely essential in giving young Americans the opportunity to attend the college or university that matches their particular needs and abilities.

The student financial assistance programs are severely underfunded. This subcommittee has heard many times that student aid appropriations have failed to keep place with inflation in the 1980s, not to mention tuition charges. The result is that many students have been forced to lower their education expectations, go heavily into debt to finance college, or forego a college education altogether. For example, in 1978, about 11 percent of all college freshmen were from the lowest 10 percent of family income ranges; this percentage had dropped to about 8 percent in 1988. In 1980, 49 percent of all college freshmen from poverty backgrounds received a Pell Grant, but this number declined to 34 percent by 1986. Over the same span, Stafford Loan borrowing by individuals from poverty backgrounds increased from 14 percent to 21 percent.

As federal grant assistance has lost ground to inflation, students have been forced to borrow larger sums. However, not all individuals feel comfortable borrowing thousands of dollars to finance college. A recent study by the American College Testing Program showed that the need for individuals to borrow more to finance college education in the 1980s, when loans became the dominant form of student financial assistance, caused half of the gains in college participation by the bottom quintile of the family income distribution in the mid 1960s and 1970s to be lost. That report concluded that "loans are not equivalent substitutes for grants for all aid applicants, especially low-income aid applicants. When loans are substituted for grants for low-income aid applicants, the enrollment problems that were solved by grants are recreated by loans."

In an effort to maintain access to independent higher education for qualified students from all walks of life, and to maintain campus diversity in the 1980s, these institutions increased their institutional grant assistance on a massive scale. Between 1980 and 1987, undergraduate institutional assistance at independent colleges increased by 84 percent in constant dollars. By 1987, these schools were providing just under $2 billion annually in grant assistance to undergraduates, far more than their students received through federal programs. In 1980, 10 percent of all educational and general expenditures at independent colleges were devoted to undergraduate student financial assistance; this number had increased to 14 percent just seven years later, in budgets that were already pinched on a variety of fronts. This effort to ensure access, therefore, has come at a price: often it has led to strained college budgets and to tuition increases.

The guiding principle of our FY 1991 request is to provide college students with more grant funds. This is the only way that more minority and disadvantaged students can be encouraged to participate in higher education, and the growing reliance on loans can be curtailed.

NAICU strongly supports a doubling of the appropriation for Supplemental Educational Opportunity Grants (SEOG) to $900 million, from the current $459 million. At hundreds of our institutions, SEOG is what prevents students from excessive borrowing. The statutory language for the program requires that priority for these awards be given to exceptionally needy students and Pell Grant recipients. Also, SEOG funds tend to flow to dependent students enrolled in college. For example, in 1987-88, two-thirds of SEOG funds went to dependent students, while for 1991-92, the Department of Education projects that two-thirds of Pell Grant funds will be awarded to independent students. NAICU is concerned that a declining share of student aid funds, particularly limited grant funds, are being received by young independent students, and

We also request that the Pell Grant maximum be increased to at least $2,500, from the present $2,300. This would send a healthy signal to collegiate aspirants and ease financing difficulties for those already in attendance. It would also restore the purchasing power of the Pell Grant to its 1982 level, measured against the Consumer Price Index.

Also, funding for State Student Incentive Grants (SSIG) should be increased from the current $59 million to $100 million. Despite the arguments of the administration, SSIG does in fact leverage state funding for both grant and work programs. During a time of austerity in the federal budget, states must be encouraged to provide student financial assistance, not discouraged. In nine states, the federal awards are matched on a 1:1 basis; federal cuts thus usually result in a loss twice as large to students. In some states, the federal-state SSIG partnership has recently become even more important as numerous state budgets have been placed under severe stress. SSIG also now provides important community service opportunities.

We also support an increase in new federal capital contributions for the Perkins Loan program from $135 million to $185 million. Perkins has a proven record in providing exceptionally needy undergraduate and graduate students with low-interest loans suited to their particular circumstances. These loans can be targeted to high-risk students, and institutions can provide appropriate counseling and follow-up on these loans.

NAICU also believes that funding for College Work-Study (CWS) should be increased from $602 million to $760 million. Again, this program reduces the need for students to borrow. The recent increase in the minimum wage to $3.80/hour makes the increase requested especially important.

NAICU also requests that $50 million over the FY 1990 level be appropriated for the institutional assistance programs authorized in Title III of the Higher Education Act (HEA). The increased funds should be divided equally between Parts A and B of the Title. We applaud the increases for this Title in FY 1990, and note that it has enabled more four-year colleges to compete for funding from Part A than in previous years.

The six programs for students from disadvantaged backgrounds (TRIO) are crucial aspects of the federal strategy for expanding access to postsecondary opportunities. Unfortunately, TRIO serves only about 10 percent of the eligible population. We support a significant expansion of TRIO services from the current level of $242 million to $509 million, which would double the current number of students served to a level of slightly more than 1 million.

The graduate scholarship and fellowship programs contained in Title IX of the HEA should be funded at $20 million above the FY 1990 level. This funding will help address the shortfall of Ph.D.s in all fields that is projected for the latter part of this decade.

## STATEMENT OF SAMUEL H. MAGILL, PRESIDENT, MONMOUTH COLLEGE

### Summary

In the past year Monmouth College has reorganized its academic programs in the high technology fields to create the School of Information Sciences and Technology. This School, comprised of the Departments of Computer Science, Electronic Engineering, and Mathematics, and the graduate program in Software Engineering, provides the only locus for instruction, research, and consulting in these fields in the region. As such, it is vital to the ongoing growth and development of high technology industry, research and development in this area.

### An Introduction to Monmouth College

Since it's founding in 1933 as a two-year institution, Monmouth has grown to become a highly respected college with a broad range of undergraduate and graduate programs. Today, Monmouth is a center for higher learning, research, and community service for New Jersey and the Middle Atlantic States. Approximately 3,200 undergraduate and 1,100 graduate students enroll in 1,200 course offerings in the liberal arts and professional curricula. Some 15,000 Monmouth alumni are making important contributions in their communities, companies, and professions.

Throughout the decade of the 1980's Monmouth has made great use of its freedom to innovate by developing new programs and revising the basic curriculum of the College. In many ways Monmouth has grown to be a small university with all the advantages of a college. It is a university in the variety, diversity, and richness of its academic programs. Unlike many larger, more impersonal institutions, however, Monmouth retains the advantages of a college in terms of the attention given to the individual needs of students. Our dedicated, involved faculty make teaching excellence their first priority. The ratio of 15 students to one professor ensures small classes with personal interaction. At Monmouth, the student remains the centerpiece.

### High Technology and the Mission of Monmouth College

In 1983 Monmouth developed and published its first strategic plan, "Strategies for the Eighties -- Goals for the Year 2000." This document, with subsequent revisions, proceeds from a realistic set of assumptions about the demographic trends affecting higher education, a careful examination of the strengths and weaknesses of the College, an acknowledgment of the geographical imperative facing Monmouth, and a collective vision about what kind of institution Monmouth College will become. It outlines the goals and objectives of the College and the steps to be taken to achieve them.

Two important themes run throughout the Strategic Plan. The first is the commitment of the College to serving the surrounding region. As the only senior institution of higher education in the central shore area, Monmouth has always had a special responsibility. Even as the College progresses toward its goal of becoming an institution recognized throughout the Middle Atlantic Region for its academic quality, its first responsibility is to the county and state in which it resides.

A second theme is the importance of high technology to the fulfillment of the mission of the College. The Strategic Plan recognizes that high technology will be one of the most important areas for study in the coming decades. The Plan outlines ways in which the College will enhance its programs in the information sciences and will use computer-aided methods to improve teaching and administration of the College.

These two themes are inextricably entwined. As more information science companies move into the area, providing education in these fields becomes a more important part of the College's service to the region. Similarly, as the region become more important to the development of the information sciences throughout the state and nation, the work of the College in these fields becomes more important to our quest for educational excellence.

## The Importance of High Technology in the Monmouth Region

The Monmouth/Ocean region of New Jersey is particularly important to the future of high technology in the state of New Jersey and the nation. A study by the Monmouth County Planning Board revealed 211 high technology companies in the County. Monmouth ranks 17th, out of the 3,100 counties in the nation, in the number of computer programming and data processing firms. Furthermore, the importance of the region to high technology research and development, industry, and service is expected to grow. A study by a national real estate brokerage firm lists the Monmouth/Ocean area as one of the top 25 areas nationwide for growth in the high technology fields in the next decade.

The large and growing role of high technology in this area, reinforces the crucial relationship between the College's programs in the information sciences and its service to the region. The importance of higher education to commercial and industrial progress in the information sciences is increasingly well recognized.

## Higher Education and the High Technology Challenge

The Report of the New Jersey Governor's Commission on Science and Technology identified several critical challenges facing the state as we prepare to enter the 21st century. The country has moved from an economy based on physical capital and natural resources to one based on knowledge and human resources. To assure that we take advantage of the opportunities inherent in the information economy, the state, its employers and workers must be able to adjust to this change.

Higher education is recognized as the key to fostering adaptation to this change and, therefore, to assuring continued economic growth. Colleges help to create the technologically-literate leadership and workforce which are necessary in an information economy. Higher education is the key to bridging the gap between research and development in the information sciences, in which New Jersey leads the nation, and the commercial application, in which the state lags. A well-developed system of higher education is crucial to increasing the "birth rate" for new information sciences firms in the state and to attracting such companies to New Jersey. Colleges sponsor joint ventures through which new ideas, the most important element of the information economy, flourish and new products and better ways of doing business are discovered.

## The Information Sciences at Monmouth College

If these advantages are to be realized in the Monmouth/Ocean region it will be through Monmouth College. Not only is Monmouth the only institution of higher education in this region offering both baccalaureate and masters degrees, it is also the only one with extensive programs in the information sciences. As such, it is the only center in the geographical area for instruction, research and college/industry collaboration in the information sciences.

Monmouth College prepared for its large and growing role in March of 1989 when it reorganized the academic programs in the high technology fields to create the School of Information Sciences and Technology. The School is comprised of the Departments of Computer Science, Electronic Engineering, and Mathematics, and the graduate program in Software Engineering.

The School of Information Sciences and Technology has a full-time faculty of 28. Some 300 students are majoring in departments of the School. In 1985 the departments now included in the School provided 4,290 enrollment credit hours of instruction. This year that number has grown to over 4,300. By 1995 we estimate that this number will climb to 4,875.

The research efforts of the School are also growing. In the Computer Science department professors are actively pursuing a sublanguage approach to Japanese-English machine translation (under an N.S.F. grant), identification and cataloging of software development tools, computer simulation and modeling, and computer graphic design. Professors within the department of Electronic Engineering are conducting research on computer imaging and data compression (under a grant from AT&T) and neural networks. In the Master of Science in Software Engineering program the professors are engaged in research on formal software specifications, C++ and object oriented programming, simulation and modeling of computer systems, and integrated software environments.

## Investment in the Future

The School of Information Sciences and Technology is preparing to meet the demand for its programs and assure New Jersey's continued success in the information age. The School is engaged in a comprehensive effort to enhance the information science programs. The important elements of this program are:

* Improving undergraduate education through curriculum redesign and enhancement, and faculty development;
* Continuing development of graduate programs, including the Software Engineering program, one of only a dozen such programs in the country;
* Providing the facilities and incentives to stimulate individual faculty research; and
* Encouraging joint College/industry research and consulting.

Keeping abreast of the state of the art is critical in any science but particularly so in the information sciences. To assure that its programs continue to provide students with the best possible education, the School of Information Sciences and Technology continuously upgrades its course offerings.

For example, the School currently is developing new courses in the following topics: * Optical Fiber Communications, * Robotics, * Computer Communications Security, and * Computer Aided Design. Undergraduate courses in all our programs are continuously being upgraded. New topics and research elements will be introduced in many undergraduate courses in the next two years including: * Physical Electronics, * Engineering Electronics, * Computer Organization, * Microprocessor System Design, * Computer Components, and * Computer Operating Systems.

In the same time frame, the graduate offerings also will be enhanced, including those in: * Neural Networks, *Computer Systems Design, *Computer Networks, * Microcomputer Design, * Computer Modeling, *Compiler Design, * Operating Sytems, * Software Engineering Environments, and * Software Process Quality.

The School is developing the human and physical resources to support these enhancements. New faculty have been hired. Faculty development opportunities have been increased. A program to bring visiting research professors onto campus has been successfully implemented this year.

Planning is underway for a $3,442,000 renovation of a general purpose academic building to establish a facility for the School. This facility will be the home for instruction and research in the information sciences, the associated computer and support operations, and a center for College/industry collaboration and consulting. The project includes the creation of ten special purpose laboratories which will greatly enchance faculty and student research. Optical fiber data communication cables will be installed throughout the computer communications and networking and greatly increasing data transmission capability.

The state of New Jersey has already committed $1.2 million from the Jobs, Science and Technology Bond Issue to this project. Companies working in high technology fields have provided over $1,000,000 in scientific equipment for the facility.

## Conclusion

The Monmouth College School of Information Sciences and Technology is a vitally important resource for the state of New Jersery and for the Middle Atlantic states. The School is critical to maintaining the high quality of instruction, research and consulting at Monmouth College, to the future of higher education opportunities in this region, and to the continued vitality of the information sciences industrial sector in the state of New Jersey and the Middle Atlantic states.

Accordingly, Monmouth College respectfully requests that the U.S. Senate appropriate approximately $29.069 billion for the various programs of the U.S. Department of Education for Fiscal Year 1991. This amount is approximately $5 billion above the appropriated level for Fiscal Year 1990 and is approximately $4.5 billion above the Administrations recommended increase for the U.S. Department of Education for Fiscal Year 1991.

We believe that the funding level of $29.069 billion for Fiscal Year 1991 is necessary for the federal level education programs to keep pace with the needs of America.

On behalf of Monmouth College, including its students, faculty, staff and alumni, I thank you for affording us the opportunity to submit this testimony for the record.

## STATEMENT OF THE UNITED STATES STUDENT ASSOCIATION

I am Janet Lieberman, Legislative Director of the United States Student Association (USSA). USSA is a national membership organization representing more than 2 million students attending diverse colleges and universities around the country. Our primary goals are to increase access to postsecondary education and to improve educational opportunity for all individuals in our nation. Thank you for this opportunity to submit USSA's recommendations for higher education appropriations in FY 1991.

During the decade of the 1990's, a vast array of challenges faces the nation. Education is a key to meeting these challenges. By the year 2000, a majority of all jobs will require a postsecondary education, and one third of the nation's school-age children will be children of color. According to the U.S. Department of Education, in 1986, 56 percent of African-American postsecondary students received federal student aid, as did 41 percent of Latin-American students, 40 percent of Native American students, 33 percent of Asian-American students, and 32 percent of White students. Over the past twenty-five years, the many student aid programs encompassed by the Higher Education Act have enabled millions of students to attend college. Over the past decade, even as it become increasingly evident that we needed to remove barriers to postsecondary education, funding for federal grants and work study actually decreased when adjusted for inflation. The trend of underfunding student aid must be reversed now, before it's too late.

### Pell Grants

Pell Grants are the cornerstone of the federal financial aid programs, providing about three million students with grant assistance. An estimated 75 percent of Pell Grant appropriations go to students with adjusted family incomes of $15,000/year or less. Over 32 percent of Pell funds assist those with family incomes of $5,000/year or less.

USSA recommends investing $7.8 billion in Pell Grants for FY 91 to fund Pell Grants at the authorized maximum of $3,100. The purchasing power of the maximum Pell Grant has dropped 16 percent since 1980 in constant dollars. The maximum Pell Grant today covers only 28 percent of the average cost of attendance, whereas during FY 80 it covered 46 percent. Increasing the maximum grant to $3100 will bring the maximum Pell Grant to approximately 35 percent of the cost of attendance and help to restore the proper balance between grants and loans.

As low and middle income students have been forced to borrow large amounts in order to attend college, it is has become increasingly evident that enormous loans are a barrier for potential students as well as an immense burden for graduates. $7.8 billion allows the Pell Grant program to serve less-than-half-time-students without a reduction in aid to full- and half-time students, and covers this year's funding shortfalls.

## TRIO Programs

TRIO Programs, Special Programs for Disadvantaged Students, are the most effective federally-funded retention programs. Serving low-income, first generation to attend college, and students with disabilities, TRIO programs reach disadvantaged high-school aged and adult students by providing the information, counselling, tutoring, and role models needed to get individuals interested in, prepared for, and able to apply to college and to remain in school. Students served by TRIO are twice as likely to complete the first year of college and four times as likely to earn a degree as are those who are not involved in TRIO.

TRIO must be funded at $508.8 million in FY 91 so that the number of TRIO students served can be doubled. The number of students served under TRIO has declined from 528,000 in 1980 to 425,000 (less than 10 percent of the eligible population) this year. USSA strongly encourages Congress to invest this amount, which will result in assistance for approximately 1 million students to enroll and succeed in postsecondary education.

## Campus-based Programs

USSA recommends funding the campus-based programs at the following levels: College Work Study, $861 million; Supplemental Educational Opportunity Grants (SEOG), $579 million; and State Student Incentive Grants (SSIG), $120 million. These appropriations would restore funding to FY 80 levels, adjusting for inflation. These programs allow financial aid administrators the flexibility to assess individual need and to award relatively small amounts of aid to students needing additional financial assistance to enroll or remain in school. Unfortunately, from FY 80 to FY 90, when adjusting for inflation, we see that College Work Study funding declined 30 percent, SEOG declined 22 percent, and SSIG declined 51 percent. Unless funding is restored, we will continue to see a growing dependence upon loans rather than grants as the primary type of financial assistance for the nation's disadvantaged students.

## Graduate Assistance

USSA recommends that Congress match the Administration's request of $6.1 million to fund the Early Identification Program and $25.5 million for Graduate Assistance in Areas of National Need. The proposed increases are commendable, but USSA opposes the President's cuts of other graduate programs USSA requests $22 million for Patricia Roberts Harris Fellowships for graduate and professional study, $4 million for the Harris Fellowships for Public Service, and $10 million for the Javits Fellowships.

People of color are grossly underrepresented at graduate schools. Enrollment of African-Americans in advanced degree programs peaked in academic year 1976-77. Are you aware that a grand total of four African-Americans earned doctorate degrees in mathematics in 1987-88? If we fail to promote the participation of people of color in higher education at the graduate level, we will continue to have extremely small numbers of professors who are people of color. It is imperative that federal funding for graduate programs be increased.

## Federal Loan Programs

USSA recommends a $286 million appropriation for new federal capital for the Perkins Loans. USSA supports the Perkins (formerly the National Direct Student) Loan program as a supplement to need-based grant programs and recommends the continuation of capital contributions into the program. Perkins Loans have the lowest interest and most manageable repayment of all the federal loan programs. Like the campus-based programs (SSIG, College Work Study, and SEOG), Perkins loans provide for flexibility on the part of the financial aid administrator to assess individual need and to deliver money to those students with exceptional need.

USSA opposes the Administration's proposed expansion of the Income Contingent Loan (ICL) pilot program. ICL was authorized as a five year, ten institution demonstration project, with a feasibility study to be completed by October of 1991. It is unwise to expand this pilot program before we have data regarding its effects. Because ICL interest lacks a fixed rate and accrues during the period of enrollment, borrowers with modest incomes will pay much more than those who immediately enter high-paying fields. For these reasons, USSA strongly opposes this program.

Thank you for the opportunity to share the student viewpoint. As walls are being torn down in Eastern Europe, millions of people are beginning to enjoy newly found rights. USSA asserts that the United States has a perfect opportunity today to dismantle barriers to colleges and universities and allow its people to enjoy the right to education.

STATEMENT OF:
AMERICAN ASSOCIATION OF COMMUNITY AND JUNIOR COLLEGES
AMERICAN ASSOCIATION OF STATE COLLEGES AND UNIVERSITIES
AMERICAN COUNCIL ON EDUCATION
ASSOCIATION OF AMERICAN UNIVERSITIES
ASSOCIATION OF CATHOLIC COLLEGES AND UNIVERSITIES
ASSOCIATION OF JESUIT COLLEGES AND UNIVERSITIES
ASSOCIATION OF URBAN UNIVERSITIES
COUNCIL OF INDEPENDENT COLLEGES
NATIONAL ASSOCIATION FOR EQUAL OPPORTUNITY IN HIGHER EDUCATION
NATIONAL ASSOCIATION OF COLLEGE AND UNIVERSITY BUSINESS OFFICERS
NATIONAL ASSOCIATION OF INDEPENDENT COLLEGES AND UNIVERSITIES
NATIONAL ASSOCIATION OF STATE UNIVERSITIES AND LAND-GRANT COLLEGES
NATIONAL ASSOCIATION OF STUDENT FINANCIAL AID ADMINISTRATORS

As associations representing all sectors of higher education, we present our recommendations on FY 91 funding for the higher education programs of the Education Department.

Our highest priority is a substantial increase in federal student grant aid. Compelling evidence of the need to expand grant assistance is presented in the recent study by Thomas G. Mortenson of ACT, The Impact of Increased Loan Utilization Among Low Family Income Students. This report directly links the declining percentage of low-income freshmen attending college to the lack of adequate federal grant resources.

Expanding access to postsecondary education is critical, if the nation is to achieve its goals for equal opportunity and economic competitiveness. In recent years the percentage of high-ability, low-income high school graduates going on to college has dropped, as has the percentage of black and Hispanic high school graduates attending higher education.

Median family income has declined over the past decade, creating increased barriers to higher education for middle-income families as well as for the poor, particularly in light of decreased levels of federal assistance measured in constant dollars. It is estimated that 82 out of 100 American children live in families that require financial aid to attend the least costly type of collegiate institution, and more than 95 out of 100 require assistance to attend an independent institution. To provide such assistance, we recommend the following increases in the federal student aid programs:

Pell Grants. This program is the foundation of all federal need-based aid, and for many students the only form of assistance they receive. Over 10 percent of federally-aided students receive only a Pell award, and over 25 percent receive only a Pell Grant and a Stafford Loan. Over three million of the neediest students in postsecondary education are served by this program, and the only way they can obtain additional assistance is by increasing the maximum award.

The Pell Grant maximum has declined 16 percent in constant dollars since 1980. It has been $2,300 for the past two years, and if it does not increase in FY 91 it will have declined 19 percent in constant dollars.

To help restore the value of the award, it is urgent that the maximum be increased substantially. An increase to $2,700 would restore the value of the Pell Grant maximum to the 1980 level. An increase to $2,500 would restore its value to that of 1982. Using the Education Department's computer model, we estimate that a $2,700 maximum would cost $6.2 billion and a $2,500 maximum would cost $5.7 billion. These are large increases, but small in relation to losing individuals who otherwise would have participated in higher education.

SEOGs. Even a substantial increase in the Pell Grant maximum will not adequately relieve the need of many postsecondary students to finance their education with excessive borrowing. We therefore recommend that the appropriation for Supplemental Educational Opportunity Grants be doubled, from $459 million to $900 million. This program, which will require 15 percent institutional matching in FY 91, assigns priority to Pell Grant recipients and students with exceptional need. An increase to $900 million would provide awards for an additional 700,000 students, thereby reducing their need for loans. The SEOG program is also important because it greatly assists students in collegiate programs.

SSIG. We also recommend an additional $41 million for State Student Incentive Grants, which serve approximately 300,000 students and require 50 percent matching funds from the states. This program provides an important incentive for need-based state grants and work-study programs; in nine states the federal contribution represents half of the total state program. Funding of $100 million would provide grants for an additional 140,000 students.

CWS. We recommend that the College Work-Study appropriation be increased from $602 million to $760 million to enable needy undergraduate and graduate students to cover a substantial portion of their need through work rather than debt. This program leverages 30 percent institutional matching funds; an increase to $760 million would provide awards for an additional 250,000 students.

**Perkins Loans**. We support an increase in new federal capital for the Perkins loan program from $135 million to $185 million to help maintain the value of the institutions' revolving funds in this important program for exceptionally needy undergraduate and graduate students. This would restore the program to its FY 89 level, and provide assistance for an additional 50,000 students. Institutions provide these loans directly to high-risk students, including small loans which commercial lenders do not make, with better counselling when the loan is originated and when the borrower enters repayment.

TRIO. The six Special Programs for Students from Disadvantaged Backgrounds are vital aspects of the strategy for expanding postsecondary opportunities. They identify qualified students from low-income families and help them to become first-generation college students by providing information, counseling, tutoring, and support to prepare for college and stay in college after they get there. The program only serves about 10 percent of the eligible population. We support a major expansion of TRIO services from $242 million to $509 million, which would double the number of students served from 502,000 to 1,004,000.

**Graduate Fellowships**. We recommend an increase of $20 million for Title IX graduate programs as necessary to meet the sharply increased demand for Ph.D.s. Specifically, we seek a $6 million increase for Part B graduate fellowships to restore the program to its prior level of 1400 new and continuing fellowships, and a $1.5 million increase in Javits Fellowships to provide for a new class of 200 in addition to continuing awards. We also support the increases requested by the Administration for National Need Training Grants and for Minority Undergraduate Internships.

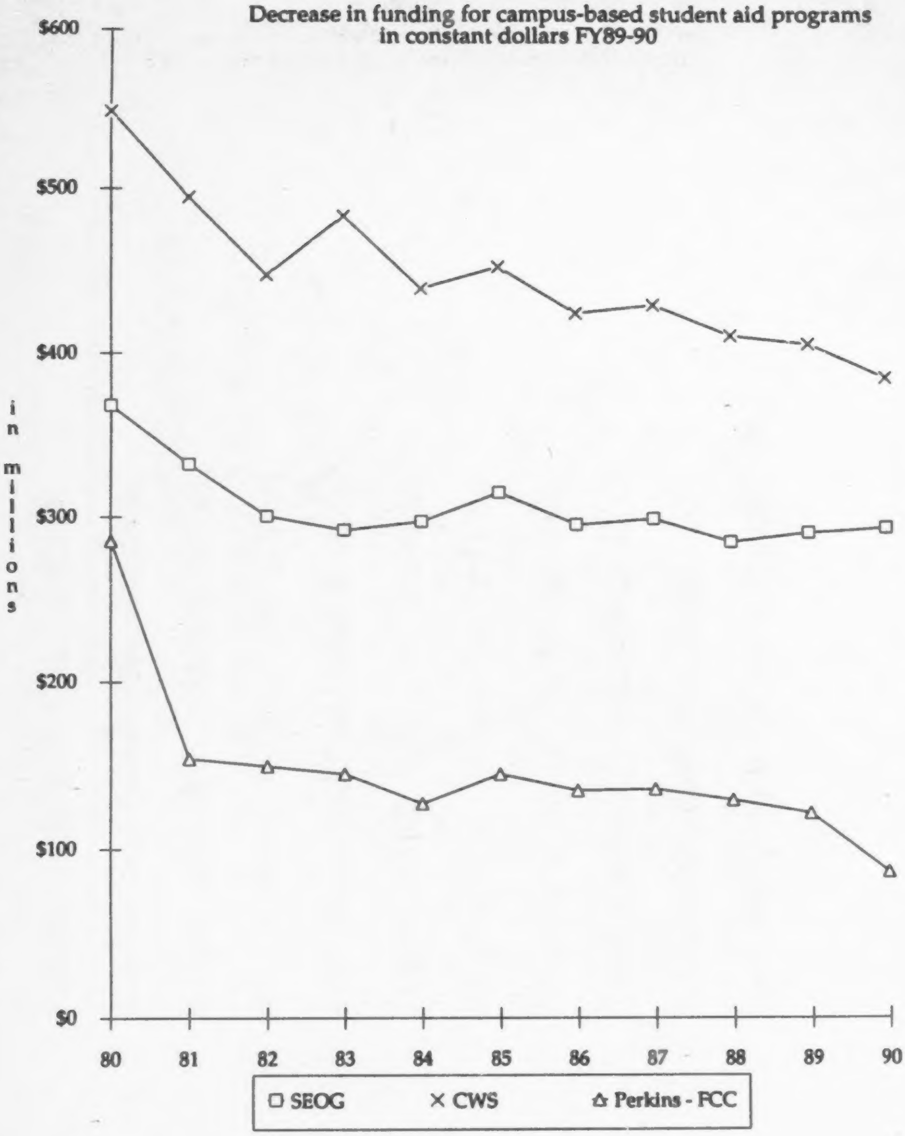
In addition to increases in student assistance programs, we recommend increases in two other priority programs:

Developing Institutions. Title III of the Higher Education Act addresses the specific developmental and endowment needs of historically Black colleges and universities and other institutions with large concentrations of minority and low-income students. Additional funding is particularly important if the educational system is to prepare adequate numbers of minority youth for careers in the sciences, teaching, and other professions. We recommend a $50 million increase for this important program.

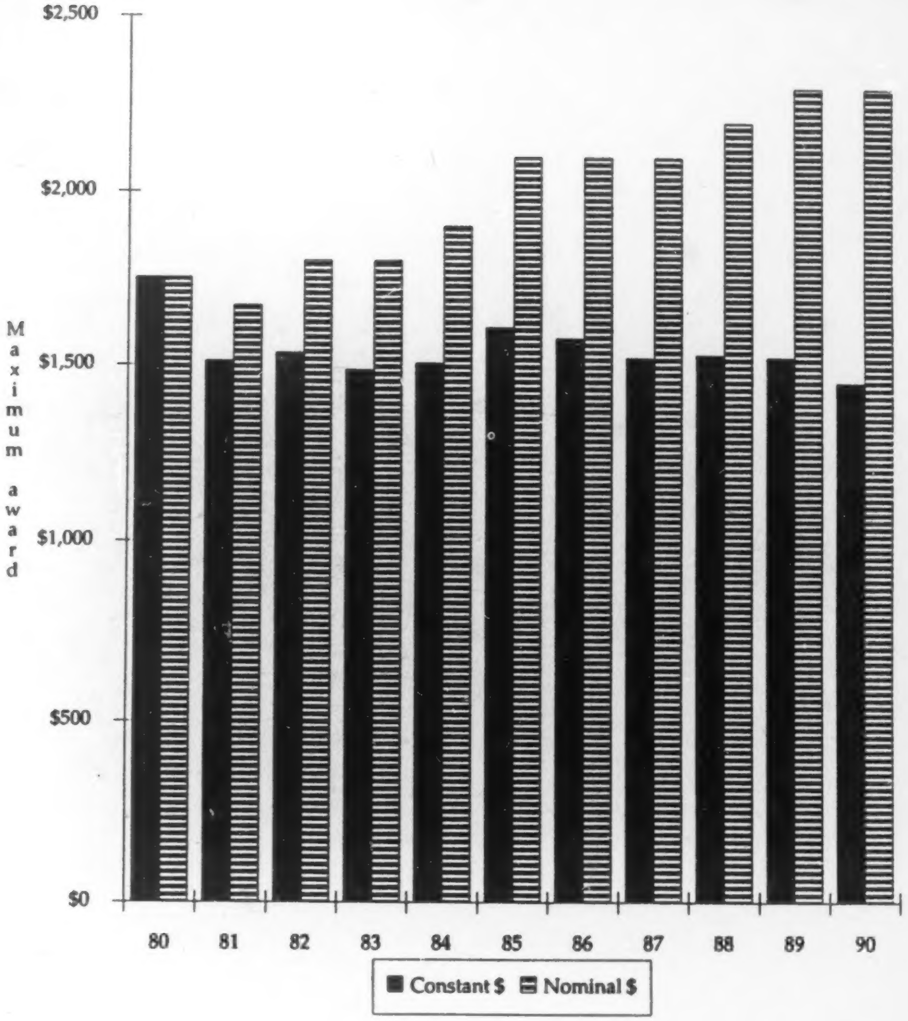
International Studies: We recommend a $10 million increase in Title VI international studies programs, primarily to increase stipends for foreign language and area studies and funding of National Resource Centers.

Finally, we urge the Subcommittee to make a careful review of the adequacy of the Department's Salaries and Expenses budget, and to issue specific guidance regarding the allocation of funds for this account. We believe that the functions for certifying institutional eligibility and performing program reviews need substantial improvement to avoid program fraud and abuse and waste of federal funds. Severe problems of understaffing exist in a number of categorical programs, such as graduate education and international studies; sufficient administrative support is a prerequisite for effective management of these programs.

Further, we ask the Subcommittee to direct the Department to resume publication and distribution of its annual Student Aid Guide. We strongly oppose the Department's decision for budgetary reasons to terminate the Guide this year. We consider it an outrage that this outstanding and effective publication was replaced with a minimal fact sheet which is much harder to read and contains less information regarding the programs and loan counselling, as the only means of informing needy students and their families about the aid available through federal programs.



Decrease in funding for campus-based student aid programs in constant dollars FY89-90



Comparison of the increase in the Pell Grant maximum award in nominal dollars and decrease in constant dollars FY80-90

## LEGAL EDUCATION

### STATEMENT OF THE AMERICAN BAR ASSOCIATION

I am Bruce Nicholson, Legislative Counsel with the Governmental Affairs Office of the American Bar Association. I submit this statement on behalf of the Association at the request of our President, L. Stanley Chauvin, Jr., to express our support for the continued funding of the Council on Legal Education Opportunity (CLEO) and the clinical legal experience program.

These two programs are modest in size, CLEO receiving $2.4 million and the clinical legal experience program $4.9 million for the current fiscal year. But they have an impact which goes far beyond their small size.

The Council on Legal Education Opportunity has been a major factor in the dramatic rise in the number of persons from disadvantaged backgrounds, particularly minorities, receiving a legal education. Our Association joined with other concerned organizations in 1968 to create CLEO as a means of addressing the problem of the underrepresentation in the legal profession of minorities and other disadvantaged persons. The program has sought to identify such persons and encourage them to apply to law school; to provide special pre-law school training to assist their entry into law school and their performance once enrolled; and to aid them financially while there.

When the program began in 1968, only one per cent of the nation's lawyers were members of minority groups. That figure has grown to more than 4%, and the figure continues to rise as the number of minorities entering law school increases each year. The percentage of minorities in the first year class at the nation's law schools this year is 14.1%, up from 13% last year. Minorities now make up 12.6% of the law school student body nationally, up from 11.6% last year.

CLEO has provided the opportunity for over 5000 students to attend law school. But beyond the students it has aided directly, the program has served to encourage law schools to increase their own efforts to ensure that all segments of society will be adequately represented in their student bodies and, ultimately, in the legal profession.

In 1986 CLEO was reauthorized to continue in existence through 1991, with authorization ceilings of $5 million for FY 87 and "such sums as may be necessary" thereafter. The Administration has recommended an appropriation of $2.46 million for CLEO for FY91, which if approved would maintain the program at its current level without adjustment for inflation.

While these amounts have enabled CLEO to increase its support last year to minority law students, CLEO stipends have significantly declined as a proportion of overall support when measured against steep increases in tuition and other costs over the past decade.

We support the requested appropriation of $3.0 million for FY90. This increase would permit first year CLEO fellows to receive stipends of $3000 rather than $2800, and second and third year fellows $2700 rather than $2500, in the coming year. This amount remains well below the stipend amounts under other federal programs for graduate and professional students, which currently provide assistance of $6000 or more. Even with this modest increase, support for CLEO fellows will remain far below the 1974 inflation-adjusted level of CLEO stipends. It would also allow for an increased number of CLEO fellows. This worthy, cost-effective program deserves and needs this modest increase.

The clinical legal experience program, which is currently funded at $4.9 million, is a much-needed supplement to the resources being spent each year by law schools on clinical legal education. These clinical programs, like their counterparts in the medical schools, permit the student to gain experience in the actual provision of services to those in need and to assume the professional responsibility of making decisions vitally affecting their clients. Clinical experience thus provides an invaluable ingredient in the student's training, greatly strengthening his or her ability to provide quality legal services to consumers upon graduation.

Such programs, however, necessarily involve close supervision and review of the students by law professors and practicing lawyers, and the student-teacher ratio must be far lower than in a conventional classroom teaching arrangement. Currently, 448 faculty members are devoting all their time to clinical professional skills programs and 1368 faculty members are devoting part of their time. While the law schools have diverted funds from other educational activities to experiment with and improve upon clinical experience programs, they are finding it increasingly difficult to support further expansion and improvement of these programs.

We believe this program has demonstrated clearly its effectiveness and should receive ongoing funding, and we urge your subcommittee to support an appropriation of not less than the current $4.9 million.

# STATEMENT OF THE COUNCIL ON LEGAL EDUCATION OPPORTUNITY

Mr. Chairman and Members of the Subcommittee:

On behalf of the Council on Legal Education Opportunity (CLEO), I submit this testimony regarding the appropriation of Assistance for Training in the Legal Profession, Title IX, Part D of the Higher Education Act of 1965, as amended, pursuant to which CLEO undertakes activities to assist individuals from disadvantaged backgrounds to obtain a legal education.

CLEO has been in operation since 1968. It was formed as a joint effort by the Association of American Law Schools (AALS), the American Bar Association (ABA), the National Bar Association (NBA), and the Law School Admission Council (LSAC), and in 1972 La Raza National Lawyers' Association (now the Hispanic National Bar Association (HNBA)) joined as a sponsoring organization. CLEO's programs were designed and continue to serve those educationally and economically disadvantaged persons who have had limited access to a legal education. While there is evidence that access to legal education has increased since 1968, in contrast to previous levels, access to graduate and professional opportunity by disadvantaged Americans continues to be an elusive goal. The goal of greater economic and political participation in the mainstream of society remains an unrealized dream for many: For example, the 1982 Annual Survey on Current Population Statistics of the Bureau of Census reports that of 606,000 lawyers in the United States, only 3.6% were members of a minority group. Currently, this percentage has increased to just over 4% of the more than 650,000 lawyers nationally.

The effort toward meaningful economic and political participation of minorities has been diligently pursued in higher education for very cogent reasons: higher education has proven to be a more effective vehicle than most for obtaining a more equitable distribution of political influence, simply because those persons most involved in the decision-making process of this country, are, themselves, products of the higher education system. This phenomenon is particularly germane to the legal profession given its role within the country's decision-making process generally and its historic lack of accessibility to minorities. The profession's impact on the formation of national policy is widely conceded because of the relationship of lawyers to all three branches of government, comprising almost exclusively the Judicial, and significant percentages of both the Legislative and Executive. It is this unique role played by the legal profession that raises compelling reasons for a continued emphasis on increasing the number of minority attorneys.

When one considers the fact that between 1963 and 1989 the number of students in law school went from 46,666 to 120,694 and that the number of minority students enrolled in law schools has stabilized at 9% over the last five years, there is little doubt that the disparity which served as a catalyst for CLEO's inception in 1968, as yet, has not been sufficiently ameliorated to warrant the termination of the CLEO program.

The CLEO program works to increase the number of disadvantaged persons within the legal profession by providing an alternate mechanism for assessing, within the law school environment itself, the potential of each program participant for the study of law. Thus, the program is designed to serve those persons who aspire and are qualified to enter the legal profession but who may be unable to gain admission to law school through the traditional admission process.

The program achieves its goal of identifying qualified law school candidates and providing the opportunity for law school matriculation via pre-law academic summer institutes for prospective law students and the provision of annual fellowships. In contrast to law schools that carry out their own summer programs for minority students who have already been granted admission to that school, CLEO is unique in that the academic preparation is provided to disadvantaged students who, but for CLEO, may not gain admission to an accredited law school. CLEO does not merely grant a living expenses stipend; it prepares students and actively advocates for their admission to law school. In fact, many students beginning the CLEO program have not yet been placed in any of the ABA-approved law schools. Thus, CLEO provides opportunity of access, which is a step that the law schools leave out via their individual one to two-week summer programs. In providing access and preparation, CLEO assures, and increases retention, graduation, and bar passage.

The academic component of the Institutes is administered by seven (7) law schools located across the country,[1] sponsored jointly by CLEO and regional consortia of ABA-accredited law schools. The Institutes are based upon the premise that significant numbers of economically and educationally disadvantaged students can be identified and prepared to successfully negotiate the law school curriculum. The Institutes mirror the law school experience by providing a six-week intensive study program in legal analysis and law development and emphasize abstract thinking, legal research and legal writing techniques. The Institutes are staffed by regular law faculty whose primary responsibility during the Institute is to evaluate each student's potential for successfully mastering the law school curriculum. Students who successfully demonstrate this potential are provided law school placement assistance and an annual stipend.

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[1] The host law schools in 1989 were: the University of California Hastings College of Law; Arizona State University; University of Missouri-Columbia; Indiana University-Bloomington; Southern University; Wake Forest University; and, Northeastern University.

The CLEO Summer Institutes have been highly successful. To date, CLEO has assisted 4,661 economically and educationally disadvantaged students to enter 175 accredited law schools throughout the country. Nearly 3,200 of these students have already graduated from law school and are now actively pursuing their careers in public service organizations, private law firms, government agencies and private industry.

CLEO has witnessed an overwhelming response to its program through the yearly number of applicants, and it is expected that this trend will continue. Last year (1989-90), over 2,000 students applied for 200 openings in the program, which attests to the continued credibility and viability of CLEO.

Data clearly demonstrates that CLEO Fellows have attained an impressive record of achievement by any measure, including performance within the academic arena of law school, bar performance, and most importantly, the employment activities of the program's graduates. The program has produced approximately 4,000 law school graduates involved in a broad spectrum of legal and law-related activities, including lawyers (public interest, private, corporate); judges; state representatives; law professors; executive administrators in various fields; Congressional staff, etc. The net result of the program has been increased access to the legal system and to the decision-making machinery of the country by those who have been disenfranchised for reason of race and/or economic status. Thus, the CLEO model of academic and financial support is one that works.

The continued success of the Summer Institutes, however, has been, to an increasing degree, dependent upon the generosity and largess of the law school community. Although authorization ceilings for the program have been set at $10 million dollars in previous years, the Legal Training for the Disadvantaged Program has received only one million dollars in appropriations since 1974; in Fiscal year 1985, the appropriation was modestly raised to $1.5 million dollars. This appropriation ceiling, in conjunction with the Gramm-Rudman-Hollings cutbacks in 1986, 1987, 1988, and 1989, has limited the number of students that can be accommodated by the program and has placed a greater burden on participating law schools to cover increasing institute, tuition and living costs from their own financial resources.

Initially, the non-federal share represented between 30-40% of the total Institute costs. However, over the last several years, the ever-spiralling costs of goods and services coupled with the effects of inflation, have thrust an even greater share of the Institutes' operating costs upon the law school. Given the fixed level of federal support, the law school community now absorbs approximately 60-70% of Institute costs, as a demonstration of their commitment to the program. The law schools, without more federal assistance, cannot continue to maintain the academic institutes, while themselves facing reduced education budgets.

In addition, the law schools are asked to provide tuition scholarships, as well as other forms of financial support in recognition of the economic needs of the students served by the program. At a time when legal education is, itself, in a difficult fiscal situation, it is extremely important to realize that $3.0 million of annual federal support for this program generates as much as $6,000,000 in cash and services annually from the law schools. And, it is unlikely that these funds will continue to be forthcoming without the catalyst provided by the Legal Training for the Disadvantaged Program through CLEO.

The financial component of the program is provided by way of annual fellowships. The provision of the stipend is contingent upon the satisfaction of several conditions: full-time enrollment at an ABA-accredited law school in the fall term immediately following participation in a Summer Institute, and the maintenance of "good standing" status throughout the duration of the grant. For the 1991 fiscal year, the $3,000,000 request will allow CLEO to assist over 614 students at the nation's law schools.

Thank you for your time and consideration.

## WRITING PROJECT

### STATEMENT OF SENATOR THAD COCHRAN

Mr. Chairman, on January 30, I introduced S. 2039, the National Student Writing and Teaching Act of 1990, to authorize funding for the National Writing Project. The National Writing Project is a network of teacher training programs affiliated with institutions of higher education to improve the quality of student writing and learning and the teaching of writing in the Nation's classrooms. There are currently 143 National Writing Project sites in forty-four states. S. 2039 would provide Federal funds on a dollar-for-dollar matching basis to be used to support the programs at each of these sites and to develop new sites. As of today, there are 28 cosponsors, including several members of this Subcommittee. The Labor and Human Resources Subcommittee on Education, Arts and Humanities conducted a hearing on March 3, which included testimony on S. 2039.

Mr. Chairman, it is my hope that S. 2039 will be authorized in time for the Appropriations Committee to provide funding for the program in fiscal year 1991.

The Writing Report Card, an assesment of writing skills of school aged students conducted by the U.S. Department of Education, recently reported that in 1988 fewer than 25 percent of our high school juniors could write an adequate letter, and most of those were filled with numerous errors.

Over the past two decades, colleges and universities across the country have reported increasing numbers of entering freshmen who are unable to write at a level equal to those demands. Over ninety percent of our postsecondary institutions currently offer remedial courses to improve the basic skills of entering students.

Business and industry leaders have testified on numerous occasions that they are concerned about the limited reading and writing skills of entry level workers.

In addition, the lack of writing ability has been recognized as a key element of the adult illiteracy problem in this country.

The National Writing Project is a teachers-teaching-teachers program that identifies what is working in the classrooms of the Nation's best teachers. It is a positive program that celebrates good teaching practice and through its work with schools, increases the Nation's corps of successful classroom teachers.

In Mississippi, National Writing Project sites have made remarkable progress in improving the quality of teaching and student learning in the State. Not only English teachers but history, geography, math, reading, science and elementary school teachers participate in the program. The result has been a measurable increase in student test scores and a rekindling of teacher enthusiasm, confidence and morale.

## STATEMENT OF JAMES R. GRAY, DIRECTOR, NATIONAL WRITING PROJECT, UNIVERSITY OF CALIFORNIA, BERKELEY

Mr. Chairman and Members of the Committee:

I am pleased to appear before you to speak on behalf of the National Writing Project.

### ABSTRACT

Writing is fundamental to student learning. It is key to educational advancement and retention, and, increasingly, it is key to job performance and advancement in the workplace. The function of the National Writing Project network is to:

- improve the writing and extend the range of writing asked of all students, kindergarten through university, in the nation's schools,
- improve the teaching of writing at all levels of instruction and extend the uses of writing as fundamental to learning in the disciplines, including mathematics, science, history and social studies, as well as English,
- extend nationwide research on the teaching of writing—including research conducted by classroom teachers, and
- expand the network of the National Writing Project into all states to serve classroom teachers in all regions of the country.

### BENEFITS TO THE NATION

The nation's teacher corps in all regions of the country and at all levels of instruction will be better trained to teach writing.

Students—all students—will improve their writing performance and will be better prepared to enter the nation's colleges and universities or the nation's workforce. They will be better able to express themselves and to put their ideas into words. They will improve their sense of self-esteem.

A national dissemination network for informing teachers of developments in research and practice in the teaching of writing and thinking will be expanded.

A nationwide, effective model of university-school collaboration will be further developed, which can continue to serve as a model of staff development suitable for teachers in all disciplines.

The efforts and accomplishments of good teachers throughout the nation will receive long overdue recognition. Teacher morale will be improved.

### BACKGROUND: THE GENERAL PROBLEM

For the past two decades, the United States has faced a crisis in English writing in schools and in the workplace. By the mid-70's, the nation's press was reporting that universities across the nation were deeply concerned over the growing number of entering freshmen who were unable to write at a level equal to the demands of college work. American businesses and corporations were concerned over the limited writing skills of entry-level workers, and a growing number of middle-level managers were reporting that further advancement was denied to them because of inadequate writing abilities. The writing problem has been further magnified by the rapidly changing student populations in American schools and the growing number of students who are now 'at risk' because of their limited proficiency in English.

## BACKGROUND: THE SPECIFIC PROBLEMS AND SOLUTION

Since 1974, the only national program to address the writing problem in the nation's schools has been the National Writing Project (NWP), a growing network of collaborative university-school programs modeled upon the Bay Area Writing Project at the University of California, Berkeley.

The writing project was established in 1973-1974 to address a number of serious problems—local problems that were echoed across the country:

- In 1973 close to 50% of UC Berkeley's entering freshmen class—bright students who had graduated in the top twelve and a half per cent of their classes—were required to enroll in the university's remedial course in writing.

- In 1973, most teachers in the schools—elementary and secondary—had not been trained to teach writing. Writing—the second 'R'—had been historically neglected. Teachers in university teacher training programs were trained to teach reading but not writing. The National Council of Teachers of English, the professional organization for English teachers, could not cite one university in the nation that offered prospective teachers a course on the teaching of writing.

- Throughout the 1970's there was little writing asked of students, either during school hours or at home. A major study on Writing in the Secondary School (Appleby, 1981) found that while students were engaged in writing-related activities 41% during the typical school day, they were asked to write at more-than-sentence length only 3% of the time.

- Traditionally, there has been little use of writing, a proven and powerful tool to promote learning and thinking, either in English classes or in other classes across the curriculum.

- Before the development of the nationwide network of the National Writing Project, there was no active dissemination network to inform and teach teachers of developments in the field of written composition.

- Before the beginnings of the writing project, neither the universities nor the schools offered systematic programs for the continuing education of classroom teachers, and the rare workshops that were offered to teachers seldom addressed subject matter issues and problems, e.g., the teaching of writing.

## THE NATIONAL WRITING PROJECT MODEL

The National Writing Project has addressed all of the above problems through the development of a model and program design based on the following basic assumptions:

1. The university and the schools must work together as partners. The "top-down" tradition of past university-school programs is no longer acceptable as a staff development model.

2. Successful teachers of writing can be identified, brought together during university Summer Institutes and trained to teach other teachers in follow-up programs in the schools. Such teachers exist in every region of the nation, teachers who have learned how to teach writing successfully since they began

teaching and are currently teaching in urban, suburban, and rural schools to the entire range of students now attending our nation's schools.

3. Teachers are the best teachers of other teachers; successful practicing teachers have a credibility no outside consultant can match.

4. Summer Institutes must involve teachers from all levels of instruction, elementary school through university; student writing needs constant attention and repetition from the early primary grades on through the university years.

5. Summer Institutes must involve teachers from across the disciplines; writing is as fundamental to learning in science, in mathematics and in history, as it is in English and the language arts.

6. Teachers of writing must also write. Teachers must experience what they are asking of their students when they have students write; the process of writing can be understood best by engaging in that process firsthand.

7. Real change in classroom practice happens over time; effective staff development programs are ongoing and systematic, bringing teachers together regularly throughout their careers to test and evaluate the best practices of other teachers and the continuing developments in the field.

8. What is known about the teaching of writing comes not only from research but from the practice of those who teach writing.

9. The National Writing Project, by promoting no single "right" approach to the teaching of writing, is now and will always be open to whatever is known about writing from whatever source.

10. Reform in education takes place in the classroom. The National Writing Project believes that the key agent in educational change is the classroom teacher who stands at the center of successful reform efforts to improve the education of the nation's students.

## THE NWP: WHAT IT DOES

Each year at all NWP sites, successful teachers of writing, K-University, are invited to university campuses for intensive five-week Summer Institutes. The aims of the institute are simple: to provide teachers a setting in which they can demonstrate their own best practices and share classroom successes; to help teachers broaden and make more conscious the grounds of their teaching through an examination of writing theory and research; to give teachers of writing an opportunity to commit themselves intensely and reflectively to the process of writing by writing themselves and by reviewing each others' written pieces in small editing response groups; and finally, to identify and train a corps of writing teachers who can effectively teach the approaches and processes of teaching writing to other teachers.

After the summer institutes and during the following school year, the teachers trained in the institutes join with other NWP Teacher Consultants who have participated in previous institutes to plan and conduct year-long staff development workshops on the teaching of writing in project-sponsored programs in the schools. By policy, these professional development workshops are voluntary. They are typically scheduled after school hours for 10 three-hour sessions spaced at intervals throughout the year. Districts and schools in the writing project's service area frequently continue this workshop series year after year.

The National Writing Project teachers-teaching-teachers reform program identifies and promotes what is working in the classrooms of the nation's best teachers. It is a positive program that celebrates good teaching practice and good teachers and—through its work in the schools—steadily increases the nation's corps of successful classroom teachers.

## IMPACT OF THE NATIONAL WRITING PROJECT

**Numbers of Teachers Trained:** Classroom teachers in all parts of the nation have responded to the teaching of fellow teachers in ever increasing numbers. Currently, approximately 85,000 teachers each year voluntarily seek training in National Writing Project summer and school-year programs. And over 600,000 teachers, administrators and others have participated in National Writing Project summer and school year programs since the project began in 1974!

**Nationwide Replication of the Writing Project Model:** The acceptance of the National Writing Project model by classroom teachers and university faculty nationwide is also evident in the extraordinary expansion of the project over the past seventeen years. Since 1973, the National Writing Project has grown into a national/international network that currently numbers 143 sites in 44 states. The National Writing Project also has 14 sites outside of the United States that serve American teachers overseas who teach in Department of Defense Dependent Schools and in U.S. Independent Schools.

**Replication of the NWP Model by Subject Matter Projects in Other Disciplines:** The National Writing Project model has been the prototype for the American Mathematics Project. In California, the California Writing Project serves as the model for the statewide subject matter projects in mathematics, science, literature, arts, and foreign languages. In Nebraska, the writing project has served as the model for the Nebraska Literature Project and in Massachusetts for the NEH/Boston Humanities Project.

**National Dissemination Network:** The National Writing Project serves as the dissemination arm of the federally-funded Center for the Study of Writing located at the University of California, Berkeley. As such, the project ensures that the Center's research is sensitive to the needs of expert teachers and that teachers, in turn, are aware of new findings and theories that support the best classroom practices.

## EVALUATION OF THE NATIONAL WRITING PROJECT

**Carnegie Evaluation:** In 1976, the Carnegie Corporation of New York funded a three-year outside evaluation of the Bay Area Writing Project/National Writing Project. This evaluation resulted in the publication of 24 Technical Reports. In his Executive Summary, the Director of this Carnegie Evaluation, Professor Michael Scriven—at that time Director, Evaluation Institute, University of San Francisco—stated that the writing project "appears to be the best large-scale effort to improve composition instruction now in operation in this country, and certainly is the best on which substantial data are available."

**NWP Evaluation Portfolio:** In 1983, the National Writing Project published the NWP Evaluation Portfolio, a collection of 32 evaluation studies conducted at sites of the National Writing Project. These studies are grouped under three categories: Impact on Student Writing, Impact of NWP Training on Teachers, and Other Measures of Impact and Effectiveness.

## IMPACT ON STUDENT WRITING

Note: The most important goal of all National Writing Project programs is to improve student writing skills, and the most important evaluation task of the NWP is to measure the impact of NWP training on participants' students. The Questions and Answers below were written by the team of evaluators who compiled the NWP Evaluation Portfolio based on present "state of the art" evaluation designs.

1. (Q) Has the model proved to be effective in its most intense form (the summer institute) as well as its less intense form of training (the school year inservice)?

   (A) Studies of student impact have found statistically and educationally significant gains in the skills of teachers trained in the summer institute as well as in the school year inservice.

2. (Q) Has the model proved to be effective in different geographical contexts?

   (A) Statistically and educationally significant gains in writing skills have been observed in rural, suburban, and urban students throughout the United States.

3. (Q) Has the model proved to be effective with students at different grade levels and at different skill levels?

   (A) Elementary, secondary, and college students possessing a range of skills (remedial to superior) have demonstrated statistically and educationally significant gains in writing skills.

4. (Q) Has the model proved effective with teachers of students from a variety of racial-ethnic backgrounds and socio-economic levels?

   (A) Studies of student impact that record statistically and educationally significant gains have included students from minority racial and ethnic backgrounds as well as students from a variety of socio-economic backgrounds.

5. (Q) Have the effects proved stable over time?

   (A) In at least two studies which lasted two or three years the students of project teachers demonstrated statistically and educationally significant gains in skills. In addition, the studies reported here have been conducted over a five year period, suggesting that the model continues to be effective.

6. (Q) Have particular methods and approaches promoted by the NWP received validation in practice studies?

   (A) A number of the particular practices presented at the different writing project sites have been validated in evaluation studies.

## IMPACT OF NWP TRAINING ON TEACHERS

Note: Even when the most conservative interpretations are made, the findings of teacher-impact studies remain highly consistent. In the evaluation studies conducted to date, teachers almost unanimously report positive changes as a result of their training. In the few cases where comparison data have been collected, the

NWP participants view their Writing Project training as more positive than any other training they have received.

1. (Q) How does the BAWP/NWP model compare with other models in teachers' perceptions of effectiveness and in their reports of changes in practices?

   (A) Compared to other training models, the existing data suggest that the NWP model produces greater changes in practices and attitudes and is perceived as more useful to participants as teachers of composition and as professional consultants than do other training models.

2. (Q) Are there differences in impact on participants observed for the more intense form of training, the summer institute, compared to the less intense form, the school-year inservice?

   (A) Teachers in both types of training report changes in approach consistent with the NWP composition model. These include adopting a process approach to teaching writing (including instruction and practice in prewriting and revising), increasing the types of writing students do, increasing the amount of writing and the number of real audiences for whom the students write. Teachers in both types of training also report similar attitudinal changes: increased enthusiasm for teaching writing, more confidence in their ability to teach writing and a resulting improvement in their students' attitudes and skills. Teachers in both groups also report a more positive view of themselves as professionals. However, increases in leadership roles such as working with peers to effect changes in curriculum and testing policies are more frequently reported by summer institute participants.

3. (Q) How effective is the BAWP/NWP training model with teachers at different grade levels and with students of different skill levels?

   (A) Teachers from elementary through college grade levels working with remedial, average, and advanced students appear to be equally enthusiastic about their training experience.

4. (Q) How effective is the BAWP/NWP training model with teachers working in subject areas other than English, including science, mathematics, art, design, and the social sciences?

   (A) Teachers working across the curriculum report that their NWP training increases their effectiveness in teaching their subjects.

5. (Q) How effectively does the BAWP/NWP model relate composition theory to composition practice?

   (A) Data suggest that the model successfully avoids a "recipes approach" to training and assists participants in relating theory to classroom practice.

6. (Q) Are reported training effects sustained over longer periods of time, up to at least five years?

   (A) Longitudinal data suggests that teachers' perceptions of project impact persist at a high level over long periods of time after their training (the longest measured being five years).

7. (Q) How consistently has the quality of training been maintained at individual sites over several years?

   (A) Data collected from different participants in successive years at the same sites suggest that training impact remains consistently high year after year.

## OTHER MEASURES OF IMPACT AND EFFECTIVENESS

Note: In addition to the evaluation of NWP impact on students and teachers, a few other types of impact and effectiveness have been examined. A sampling of findings from a number of these studies is reported below:

1. (Q) How consistently is the BAWP-NWP training model replicated at sites across the country? What are permissible local adaptations?

   (A) A survey of NWP site directors suggests that the basic features of the model are consistently incorporated at each site, with adaptations occurring in some operational features of the programs.

2. (Q) What other types of impact occur at the level of the school, the district, the university, and the state?

   (A) NWP programs appear to be contributing to changes in curriculum, course offerings, and educational policy at school districts, university, and state levels.

3. (Q) How cost-effective is the BAWP-NWP model? How does its development and operational costs compare with those of other professional development and curriculum projects?

   (A) A study of the cost of the training model in comparison to other training and curriculum development projects suggests that the model is highly cost effective.

**A Sampling of Recent Local Site Evaluation Studies:**

1. Bay Area Writing Project. Teachers at Bret Harte Junior High School in Oakland, California, in collaboration with the Bay Area Writing Project, conducted a pre-post schoolwide (grades 7, 8 and 9) writing assessment to evaluate the effects of their teaching after over 100 hours of Bay Area Writing Project inservice. Approximately 70% of the students improved overall relative to their performances on the pretest. On the specific dimensions, 65% improved in fluency, 56% improved in sentence development, 62% improved in specificity, 66% improved in organization, and 61% improved in providing illustrations and/or examples. Overall, 83% of the English as Second Language (ESL) students improved. In addition, more students improved in the second year of the pre-post assessment than in the first. Sixty-two percent of the students improved in 1988; 70% improved in 1989. Ninety-seven percent of the Bret Harte students are minority.

2. New York City Writing Project. The Writing Teachers' Consortium, (W.T.C.) is a staff development and support program designed by the New York City Writing Project in cooperation with Lehman College. The W.T.C. program has been a joint project of Lehman College and the Board of Education since 1984-85. The Office of Research, Evaluation and Assessment (OREA) conducted a comprehensive evaluation of the 1987-88 W.T.C. program,

collecting both quantitative data on students and qualitative data about teachers and program implementation at all participating eleven high schools.

Findings show that teachers clearly increased their use of a range of writing techniques. Student outcomes were positive as well. Eighty-eight percent of Core students but only 72% of control group students received passing scores on the composition section of an unsecured version of the Regents Competency Test (R.C.T.) in Writing ($t=3.42$, $p<.001$) and students in the 1986-87 Core program (87%) passed the writing R.C.T. at a significantly higher rate than control group students (80%) (chi square = 13.92, $p<.0002$). There was a trend toward higher attendance in Core group students although reading scores did not differ between Core and control group students. Core group students' attitudes toward school were high and remained so throughout the program.

3. Mississippi Writing/Thinking Institute. In 1987, the Mississippi State Department of Education asked the Mississippi Writing/Thinking Institute (Mississippi's network of National Writing Project sites) to develop a remedial reading and mathematics curriculum and accompanying staff development for teachers. The curriculum was developed with a clear understanding that writing-to-learn and writing process would be the primary approaches to learning and that skills would be taught in a meaningful context, not in isolation. The eight-week pilot program involved 1,500 high school or drop-out students. A gain of four months in each subject area was expected. The actual gain in reading averaged 1 year, 7 months; the mathematics gain averaged 1 year, 9 months.

   The Mississippi Writing/Thinking Institute has since developed a school-year remedial curriculum consisting of a reading course, a math course, and a writing course along with intensive staff development for teachers. The program is in use in Mississippi high schools with students who have failed or who are at risk of failing the Functional Literacy Examination, a requirement for graduation in Mississippi. Teachers report that students benefit in academic achievement and attitudes about school and that teachers experience renewed enthusiasm for teaching, a result of the staff development accompanying the program.

4. Caprock Writing Project. In the Lubbock, Texas area, the performance of Morton Independent School District fifth graders serves as a dramatic example of project impact. In 1985, four months before the Caprock Area Writing Project began, 34.5% of these students, 62% of whom were Hispanic, failed the state writing exam. By 1988, their teacher, a first-year Caprock participant, had changed the failure rate to 3% and the pass rate to 97%. Based on this exceptional leap in achievement, the Exemplary Programs Division of the Texas Education Agency recognized both the district and the Caprock Area Writing Project as centers of excellence.

5. Boston Writing Project. The Boston Writing Project works closely with the racially and linguistically diverse schools of the Greater Boston Area, and has on file evaluation findings which demonstrate that multicultural approaches to the teaching of writing improve teacher effectiveness and morale and can dramatically improve students' motivation and writing skill. An outstanding case in point occurred last year when Boston Writing Project Teacher Consultant Judith Baker, an English teacher at Boston's Madison Park High School, turned a group of students which included many reluctant writers and non-writers into a highly motivated staff of reporters and writers for a special anti-drug issue of the school newspaper. The students produced

well-written news stories, interviews, op ed essays and poems around the theme "Cocaine: A New Slavery." The resulting publication was so successful that thousands of copies of the paper have been reprinted and are being used as curriculum material in Boston classrooms.

## HONORS AND RECOGNITIONS

**In 1978**, the University of California, Berkeley Bay Area Writing Project received the annual Western Electric Award in Education "in recognition of outstanding achievement in meeting today's educational needs."

**In 1984**, at the culminating event of the American Association for Higher Education's Annual Conference on Higher Education, the National Writing Project was honored "as an outstanding and nationally significant example of how schools and colleges can collaborate to improve American education."

**In 1987**, at the final meeting of the National Council of Teachers of English Annual Convention, the National Writing Project was honored and recognized as "an exemplary national resource."

**In 1988**, in the final report of the two-year evaluation of staff development programs in California funded by the California Legislature and conducted by the Far West Laboratory for Educational Research and Development and by Policy Analysis of California Education (PACE), the California Writing Project was recognized as "one model that deserves attention for university-based staff development," and as a project "which has earned the admiration of teachers and administrators throughout the state," and as a project that "has served as a model for other university-sponsored staff development programs."

**In 1989**, the National Council of Teachers of English (NCTE) granted the profession's annual premiere recognition of achievement, the Distinguished Service Award, to the National Writing Project Director.

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"As for the character of the work, I have no hesitation in saying that the National Writing Project has been by far the most effective and 'cost-effective' project in the history of the Endowment's support for elementary and secondary education programs."

--John Hale, National Endowment for the Humanities

"The model staff development program you have developed, that has universities working together with schools at all levels, merits the support of those who value excellence in education. Your project gives some of the most dedicated and capable teachers the vital nourishment they need,"

--William Bennett, Secretary of Education

"The National Writing Project has done more than anything else in this country for the teaching of writing."

--Peter Greer, Deputy Undersecretary, Department of Education

"[BAWP] has stirred up English teachers to an extent that I have seldom if ever seen. I was closely involved in the work of some of the research and development centers established by Project English, but none of them started what one would call a 'movement.' I now believe that the Bay Area Writing Project really has started a movement that is sweeping the country.... With all my bias in favor of hard data, I am already pretty sure that this is one of those ideas that will last—like Langdell's invention of the case method of teaching law about 1870."

–Paul Dietrich, Educational Testing Service

"There would be a terrible void in American education had there been no National Writing Project."

–Roger Rosenblatt, Time Magazine

"If I were an administrator, I'd want to get every teacher in my school out to the Writing Project; I wouldn't consider hiring any unless they had been trained by it."

–James Squire, Former Executive Director, NCTE

"There is absolutely no doubt in my mind that the Writing Project is the best thing that has happened to our region and our state in my twelve years of teaching. This year alone, I have worked with over 200 teachers, this in a rural and mountainous area where schools are isolated and distant from our campus. Through the Project, teachers have been able to meet and learn about writing and more, and their lives have been changed. That sounds, perhaps, melodramatic, but it's the truth."

--Charles Whitaker, Director, Eastern Kentucky Writing Project

Finally, the project continues to be cited by the local and national press for its major role in improving the quality of education in the country with prominent stories in the *New York Times, Washington Post, Los Angeles Times, Newsweek, U.S. News and World Report*, and *Phi Delta Kappan*, as well as in popular family publications and on national television networks. An education reporter for the *Sacramento Union* once referred to the project as "the one education program in California that only has friends."

## THE NEED FOR FEDERAL SUPPORT

**(1) The National Writing Project seeks federal support to provide for the continued development of the project and regular support for all sites within all states and regions of the nation.**

The basic goal of the National Writing Project is to improve the quality of student writing and the teaching of writing in all regions of the country. To do this, the NWP must develop an expanded network of at least 250 sites nationwide. Currently the national project is growing at the rate of approximately five new sites each year; this rate of development will increase with federal support.

In addition to the need to develop and expand the NWP network of sites is the need to provide on-going support for sites within the national network through a combination of federal, state, and local support. At present the funding levels of local NWP sites varies considerably; no sites within the network are adequately supported, although some are more financially stable than others. Currently, only twelve states provide some degree of state funding for their networks of sites (California, Virginia, West Virginia, North Carolina, Hawaii, Alaska, Kentucky, Connecticut, Nevada, Mississippi, Louisiana, and Pennsylvania). Federal support in the form of matching funds will hasten the development of state-supported networks of NWP sites as well as provide needed stability for the National Writing Project network.

**(2) The National Writing Project seeks federal support to provide the funding needed to support NWP networking activities and NWP administration.**

Equally important is the need to provide funding for the lead agency of the National Writing Project. While local NWP sites and the statewide networks of NWP sites receive support from their sponsoring universities, from surrounding school districts, and—in the twelve states listed—from direct state funding, there is no comparable funding for the National Writing Project itself. The national project—which provides matching funds to all new sites, which conducts, supports, and maintains all of the networking, quality control and dissemination activities that tie the local sites into a coherent nationwide program, and which handles all national administration—has no national support. The NWP has had to rely primarily upon extramural funding from private foundations. Yet private foundations are unwilling to maintain programs over time—no matter how successful those programs have been! The many rounds of grants the project has received from the National Endowment for the Humanities and the Carnegie Corporation of New York and other foundations have finally come to a close. The Andrew W. Mellon Foundation, which currently supports new site development, has given the NWP a third grant. To help make the project more self-supporting, the NWP established in 1987 a national sponsorship campaign that generates support from the institutions and classroom teachers who participate in the National Writing Project. This campaign now pays for itself and does provide some level of administrative support, but such a teacher-centered fundraising effort will never be sufficient to meet the national need.

# DISABILITY EDUCATION

## STATEMENT OF THE AMERICAN FOUNDATION FOR THE BLIND

The American Foundation for the Blind is a national nonprofit organization whose primary mission is to ensure the development, maintenance, and constant improvement of services for blind and visually impaired people in the United States.

Recognized as Helen Keller's cause in the United States, AFB works in partnership with more than 1,000 specialized agencies, schools, and organizations of and for blind people.

AFB fully supports the appropriations recommendations of the Consortium for Citizens with Disabilities and the Coalition on Technology and Disability . Because of space limitations our statement will highlight only those programs on which we believe we can provide a unique perspective.

(All dollar figures are in millions)

*Special Education Personnel Development*

| FY1989 Appropriation | FY1990 Appropriation | FY1991 Authorization | President's FY1991 Request | AFB FY1991 Recommendation |
|---|---|---|---|---|
| 67.09 | 71.0 | pending | ---[1] | 95. 0 |

This funding level would return this program to the level authorized prior to the authorization reductions of the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35). We are seriously concerned about the shortage of teachers who are trained to deal with the unique needs of blind and visually-impaired children. Congress needs to fund these programs at the recommended level to insure an adequate supply of qualified personnel who can instruct blind children in such skills as orientation and mobility and the use of braille.

*Special Education Technology*

| FY1989 Appropriation | FY1990 Appropriation | FY1991 Authorization | President's FY1991 Request | AFB FY1991 Recommendation |
|---|---|---|---|---|
| 4.73 | 5.42 | pending | ---[2] | 11.9 |

Access to adaptive technology, such as talking computer terminals, has a significant impact on appropriate education for children who are blind or visually-impaired. Accordingly, Congress should fund part G as recommended to assist in the development and availability of new technologies.

*State Operated Programs (P.L. 89-313)*

| FY1989 Appropriation | FY1990 Appropriation | FY1991 Authorization | President's FY1991 Request | AFB FY1991 Recommendation |
|---|---|---|---|---|
| 148.2 | 146.39 | formula | 146.39 | 170.0 |

AFB believes that state-operated and state-supported schools for blind children are an important part of the continuum of placement options for blind and visually-impaired children, especially those who are multi-handicapped.

***Rehabilitation Services--Independent Living Services for Older Blind Individuals - Title VII, Part C***

| FY1989 Appropriation | FY1990 Appropriation | FY1991 Authorization | President's FY1991 Request | AFB FY1991 Recommendation |
|---|---|---|---|---|
| 5.7 | 5.9 | 6.56 | 5.83 | 6.56 |

By the year 2000, the number of people over age 75 will increase by 56 percent. Persons who become blind at a young age can be expected, for the most part, to share in this longevity. Also, blindness or visual impairment is often associated with the aging process. The fully authorized amount of $6.3 million is, in fact, inadequate to meet the growing needs of this population. An effort will be made to reauthorize this program as a formula grant with a substantial increase in authorized funds when the Rehabilitation Act is next reauthorized.

***Technology-Related Assistance Grants***

| FY1989 Appropriation | FY1990 Appropriation | FY1991 Authorization | President's FY1991 Request | AFB FY1991 Recommendation |
|---|---|---|---|---|
| 5.2 | 14.8 | such sums | 20.0 | 30.9 |

(National Programs--Title II)

The Technology-Related Assistance for Individuals with Disabilities Act (P.L. 100-407) is a new discretionary program created to increase access to assistive technology devices and services for individuals of all ages and disabilities.

AFB strongly believes that the full participation of all states is needed to insure the development of comprehensive and coordinated systems of delivery for assistive devices and related services. In addition, funding for Title II activities, such as the authorized study by the National Council on Disability concerning financial and other barriers to the acquisition of needed technologies, is necessary particularly since technology is an important component of the effective education, rehabilitation, and productive life of blind and visually-impaired people.

***Media and Captioned Films***

| FY1989 Appropriations | FY1990 Appropriations | FY1991 Authorization | President's FY1991 Request | AFB FY1991 Recommendation |
|---|---|---|---|---|
| 13.34 | 15.19 | pending | —[3] | 16.1 |

AFB recommends an increase in the appropriation for the media and captioned films account (Section 653 of the EHA). Our recommendation would permit second year funding ($1 million) for video description services. Video description provides to blind persons a narration of the visual information presented on a television screen. Although the earmarked funds for video description services for FY1990 have not yet been obligated by the Dept. of Education, we believe that second year funding of this activity is vitally necessary so that the number of video described television programs and other materials can be expanded.

***Special Institutions--American Printing House for the Blind***

| FY1989 appropriations | FY1990 appropriations | FY1991 authorization | FY1991 Presidents Request | AFB FY1991 Recommendation |
|---|---|---|---|---|
| 5.34 | 5.66 | such sums | 5.90 | 5.901 |

We recommend an increase for the American Printing House for the Blind over last year's funding level inasmuch as the number of students to be served continues to grow even though the appropriation for the Printing House has remained fairly constant over the past ten years. In addition to braille and talking book production, APH develops unique educational products which benefit blind children.

1. Legislation is pending to reauthorize discretionary activities under the Education of the Handicapped Act. An Administration request should be forwarded when authorizing legislation is enacted.

2. See Endnote 1.

3. See Endnote 1.

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## STATEMENT OF THE UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

UCPA is a national network of 182 affiliates in 45 states advocating for and providing community services to persons with severe disabilities and their families to assure their increased independence, productivity and integration into the community. Collectively, UCPA spends over $300 million a year on a broad range of services for children and adults with severe disabilities. UCPA is concerned with all the issues identified by the Consortium of Citizens with Disabilities but has chosen to describe the five most important to persons with cerebral palsy.

**SUPPORTED EMPLOYMENT:** For the past four years, funding for Title VI of the Rehabilitation Act, P.L. 99-509, has enabled supported employment programs across the country to assist individuals with disabilities become part of the work force in diverse business and industry settings. One such individual is Charles Muluasi of New Jersey, a 43-year-old man with cerebral palsy who uses a powered wheelchair for mobility which he controls with two fingers on his right hand. Despite 5 years of volunteer work for Atlantic County Office for Aging and Disabled and the Kessler Memorial Hospital

Pharmacy, Charles was never offered a paid position at either job. Furthermore, when Charles asked for a paid position at Kessler Memorial, the personnel manager felt he could not "handle" the demands of the job. Through the Division of Vocational Rehabilitation (DVR) and UCP/Atlantic and Cape May Inc.'s Supported Employment Program, however, a meeting was arranged to discuss work-site modifications necessary to employ Charles as a data entry clerk. UCP's rehabilitation technologist agreed to do the worksite modifications with the help of hospital staff. Charles DVR counselor approved the IBM computer, monitor and printer for his worksite. One of the unique aspects of Charles' approach to his job is that he inputs all data with his tongue, typing at a rate of 25 words per minute. Charles earns $6.50 an hour and receives full medical coverage and life insurance.

Since enactment of the 1986 amendments, the number of people in supported employment has increased dramatically. However, people with severe physical disabilities are significantly underrepresented in this program. Indeed, recent data from the U.S. Department of Education indicated that only 0.6 percent of people in supported employment are individuals with cerebral palsy. The President's budget request will, at best, allow state agencies to continue to serve only a fraction of eligible individuals with severe disabilities. UCPA recommends $30.94 million for this important program in order to reduce dependency and increase economic productivity of citizens with severe disabilities.

**FAMILY SUPPORT:** A critical priority for persons with disabilities and their families is family support services, including respite care. Family support recognizes that families are the primary caregivers for their children with disabilities and that the government should support rather than supplant the family so that all children have to right to grow up at home. P.L. 100-401, the Temporary Child Care for Children with Disabilities and Crisis Nurseries Act, is a vehicle for federal leadership to assist states to plan and develop a system of family support. A February, 1990 survey Family Support Services in the United States: An End of Decade Report compiled by Human Services Research Institute and funded by the Administration on Developmental Disabilities within the Department of HHS finds that no state has taken a comprehensive interagency approach to family support in an effort to maximize access to available resources. Although every state has concluded that family support is something that it should offer, most states remain undecided about the direction these efforts will take. Nationally, and in most states, the actual fiscal commitment to family support is less than 2%

of the total budget allocated for developmental disabilities services; facility-based programs continue to absorb the bulk of the resources. Here is how two families in Alaska use respite as a family support service:

> Sharon Mattingly lives in Fairbanks with her husband and three children: Bart, 10; Whitney, 3; and Regan, 4. Bart is a child whose ability to learn is severely impaired and who is also hyperactive. He requires a very strict routine throughout the day, as well as constant supervision. Bart often uses "attention-getting behaviors, temper tantrums and outbursts, seeing how far he can go with you...." Bart had been to every day care and private child care program in the county without success. For the Mattingly's, the respite care program run by Fairbanks Rehabilitation Association is the only option. The family uses the program while Sharon and her husband have some time together with other family members.
>
> Jane White is the mother of three children, including a daughter, Jenny, age 11, with severe disabilities and whose behavior can be unpredictable and difficult. The Whites have used the respite care program to allow them the opportunity for vacations,"It gives us time to be a family in a more normal-type way. If we had Jenny with us, probably 50% of the time would be spent coping with Jenny.... It gives my other children a chance to see their parents in a normal relationship. The other kids in the family need the respite too...."

The President's request for level funding comes at a time when states, burdened by the "drug crisis," are being asked to serve more abandoned, neglected and abused children in community-based settings. The President's budget will produce incremental expansions of small pilot projects available to only a few areas of some states. UCPA recommends $20 million for FY1991--an amount consistent with the 1989 reauthorization level and an amount equal to less than 1 percent of the federal Medicaid matching funds ($3.38 billion) for public and private institutions (ICFs/MR).

**TECHNOLOGY-RELATED ASSISTANCE FOR INDIVIDUALS WITH DISABILITIES:** When the New Jersey Rehabilitation Technology Resource Center (RTRC) opened its doors on February 1, 1989, it also opened up new horizons for thirteen-year-old twins, Matt and Jason Payton of Trenton, N.J. When Matt and Jason, who have cerebral palsy and use wheelchairs, toured the RTRC on its opening day, rehabilitation technologists and RTRC staff showed the boys a variety of ways that technology could enhance their lives and increase their independence. Jason tried out a powered wheelchair that also was equipped with environmental controls. Not only could Jason move about the Center more easily and comfortably, but he also delighted in his ability to turn on a TV and switch a light on and off without asking for help. Jason and Matt, already avid computer buffs, also experimented with a computer table that can be easily adjusted to fit the needs of the user simply by pushing a switch. As Matt exclaimed, "It seems like I have the whole world at my fingertips!" In the few months since the RTRC opened, 428 persons with disabilities and their families have visited the Center. The Center provides individuals with disabilities access to the type of technology that can enable them to lead more independent, productive lives.

The President has requested a $5 million increase for the Technology-Related Assistance for Individuals with Disabilities Act, $20 million for FY1991. This request would support approximately 25 Title I continuation grants, 10 new state grants, and technical assistance to states. States funded as of 5/1/90 are Arkansas, Alabama, Colorado, Iowa, Indiana, Illinois, Kentucky, Maine, Massachusetts, Minnesota, Maryland, Mississippi, Nebraska, Nevada, New Mexico, North Carolina, Oregon, Tennessee, Vermont, Virginia, Wisconsin, and Utah. The program, now in its third year, is intended to fund all remaining states. The President's request falls about 15 states short of this goal. In addition, the evaluation study must also be funded this fiscal year in order to meet the mandated deadline for the report to Congress. Title II programs on financing, personnel preparation and training, and public awareness would not be funded. Therefore, UCPA recommends $30 million for P.L. 100-407.

**EARLY INTERVENTION:** Amanda was born with severe disabilities including cerebral atrophy, seizure disorder, blindness with left glaucoma and hydronephrosis. A little more than a year ago, when she was 13 months old, Amanda was first enrolled in the early intervention program run by UCP of the Capital Area, in Camp Hill, Pennsylvania. At first, Amanda did not seem to do anything intentionally to control people or events -- what little she initiated seemed to be unrelated to things going on around her. Last year Amanda's parents and the staff saw no evidence of learning, nor did Amanda have any preferences or motivation to play. Amanda showed no progress when measured by traditional developmental checklists.

The early intervention staff and Amanda's parents were unsure about Amanda's future but were in agreement on at least three things: They all wanted her to be able to be productive, to control her world, and be happy. They agreed that technology would help.

After 5 months trial and error with different devices to control her environment and introduction to adapted toys, the real Amanda was liberated. Today, Amanda is 2 1/2 years old. She plays happily with her mom with a five-plate busy-box. Activating each of five switches produces a different consequence including a radio tuned to her favorite station. Besides making choices among the switches, Amanda actively engages in play and simply has fun. Early intervention with the assistance of technology will enable Amanda to enter preschool at the appropriate time.

The Administration's FY1991 budget request provides a 4% increase over FY1990 to $82.7 million for Part H of EHA (P.L. 99-457). While the President recognizes the importance of early intervention as indicated by his sizeable increase for the Head Start program ($500 million), the Administration fails to see its importance for children with disabilities. UCPA recommends $160 million for FY1991 in order to ensure the necessary fiscal incentives for all 50 states to pursue full implementation of this important cost-effective program.

**ALLIED HEALTH SHORTAGES** The Omnibus Health Programs and Extension Act of 1988 (P.L. 100-607) provides for advanced training of allied health personnel. The education system for rehabilitation professionals has not been able to meet the demand for core rehabilitation therapists. The demand will reach crisis proportion next year (school year 1991-92) when states must serve all eligible children with disabilities as mandated in P.L. 99-457. A 1988 study by the Institute of Medicine projects that by the year 2000, "the demand for physical therapists will increase by 87 percent... occupational therapists by 52 percent." The report declares that unless policymakers intervene, the health care industry will suffer from a "serious shortage of allied health professionals." Our national UCPA office frequently hears from our affiliates and other providers requesting help in this area. Current levels are not meeting the present demands, and services to persons with disabilities are compromised. UCPA recommends full funding of this essential program.

Thank you for the opportunity to present information on behalf of individuals with disabilities and their families.

# EDUCATION AND NATIVE AMERICAN HAWAIIANS

## MEMORANDUM FROM THE CONGRESSIONAL RESEARCH SERVICE

March 5, 1990

**TO:** Senate Select Committee on Indian Affairs
Attention: Yvette Joseph

**FROM:** Roger Walke
Analyst in American Indian Policy

**SUBJECT:** Trends in Indian-Related Federal Spending, FY1975-1991[1]

This memorandum responds to your request that we update the analysis of Indian-related budget areas presented in the "Special Features" section of the Committee's publication *Budget Views and Estimates for Fiscal Year 1989* (S. Prt. 100-116), to cover the fiscal years 1975-1991.

The memorandum summarizes trends in most Indian-related areas of the Federal budget over the period FY1975-1991. The budget items selected usually account for 70 percent or more of total Federal spending each year on American Indians and Alaska Natives.

The trends are summarized in tables 1-4, and selected trends are illustrated in graphs 1-18. Both tables and graphs are based on the data in appendix tables 1-2. For each budget area, tables 1-4 show (1) the average level of spending in each year over the time period, (2) the annual change (i.e., the annual trend) in such spending, (3) the annual trend as a percentage (here called the "change ratio") of the average level, and (4) an indicator of the consistency of the trend.

Table 1 covers the period FY1975-1991, using current dollars. Table 2 covers the same period using constant, or inflation-adjusted, 1982 dollars. Tables 3 and 4 present the same current- and constant-dollar data for the period FY1982-1991.

This memorandum emphasizes constant-dollar figures. Since such figures are adjusted for the effects of inflation, they are better indicators of real changes in spending.

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[1] Data for this analysis was updated by Garrine Laney, Analyst in American Indian Policy.

This memorandum is not intended to be a complete analysis of all the Indian-related budget items selected. Rather it is meant to compare trends in major budget items affecting the nation's Indian population with trends in parallel budget items affecting the entire U.S. population. After a discussion of methodology and sources, the memo focuses on budget items in three topical areas -- education, health, and housing and economic development -- before examining overall trends.

## METHODOLOGY AND SOURCES

The Indian-related budget items chosen for this analysis are the Bureau of Indian Affairs (BIA) in the Department of the Interior, the Indian Health Service (IHS) and the Administration for Native Americans (ANA) in the Department of Health and Human Services, Indian education under the Department of Education, and Indian housing under the Department of Housing and Urban Development. According to the Office of Management and Budget, these agencies accounted for 75 percent of Indian-related spending government-wide in FY1988 and 74 percent in FY1989 and FY1990.

Spending by agencies is measured in terms of either appropriations or outlays, depending on data availability and past usage in the Committee's study of FY1989. Indian housing data were available in terms of use of budget authority.

To adjust for inflation, current-dollars figures were changed into constant dollars. The base year for the constant dollars was 1982, and the inflation index used to compute constant dollars from current-dollar figures was the Implicit Price Deflator for the Gross National Product. We chose Implicit Price Deflator instead of the Consumer Price Index (CPI) because the former accounts for inflation in the entire economy rather than just in consumer purchases, and hence is more appropriate for the full range of Indian budget areas.

The average, or mean, level of spending during the period FY1975-1991 was computed by dividing total spending over the time period by the number of years.

Annual change (annual trend) and trend consistency over the time period were determined by a time-series linear regression analysis. Such an analysis attempts to find the best straight line illustrating the relationship between a variable (here, a budget item) and time. The annual change is the "slope" of such a straight line (also known technically as the "coefficient of X" or the "regression coefficient"); the slope shows how much the spending on a budget item changes for every year that passes. Trend consistency is the "coefficient of determination," or $r^2$, generated by a regression analysis. Here, $r^2$ can be interpreted as follows: if the $r^2$ is high (i.e., closer to 1), then the trend, whether up or down, is very consistent; if the $r^2$ is low (closer to 0), then the trend is very irregular.

"Change ratio," expressed as a percentage, denotes the annual change divided by the average level of spending. This is to control for the fact that the size of a budget item's annual change will vary with the total amount of dollars spent by an agency. It illustrates that an annual change of $10 million, for instance, for an agency spending $100 billion is a much lower increase, proportionally, than the same $10 million increase for an agency spending $50 million.

Sources for budget data are the respective agencies and the annual *Budget of the United States Government* submitted by the President. Budget data collected included historical appropriations and outlays and FY1991 budget estimates, by agency and by budget function[2] category. Agencies contacted include the BIA, IHS, ANA, HUD, Education Department, Interior Department, U.S. Forest Service, U.S. Fish and Wildlife Service, Bureau of Land Management, and the Minerals Management Service. It should be noted that HUD was not able to provide Indian housing data for FY1977 because the data had been archived.

U.S. population data came from the *Statistical Abstract of the United States*. Indian population data came from the Indian Health Service's *Trends in Indian Health 1989* and are based on that agency's service population. This figure is useful because it is updated annually.

Historical figures for the Implicit Price Deflator were obtained from the *Economic Report of the President* (February 1990); projections for 1990 and 1991 came from Data Resources, Inc. (DRI).

## EDUCATION

Education data from table 1 show that Indian education spending appears to have been growing from FY1975 to FY1991. The annual change for BIA education, for instance, shows an increase of $2.6 million (change ratio of 1.00 percent) per year. These figures, however, are in current dollars. Inflation has not been taken into account. The constant-dollar figures in table 2 do take inflation into account. These data show that BIA education has actually fallen by $11.8 million (-4.21 percent) a year during the period FY1975-1991. This pattern -- an apparent current-dollar increase belied by a constant-dollars decline -- is repeated in most Indian-related budget areas.

Table 2 shows that the Department of Education budget has averaged $15.2 billion in constant 1982 dollars during FY1975-1991 and has grown at a rate of $193.2 million (1.27 percent) a year, but with substantial annual variation ($r^2$ of .332). In contrast, Office of Indian Education programs in the Department of Education have averaged $70.4 million a year in constant dollars in the same time period and have fallen $2.4 million (-3.44 percent) a year. The $r^2$ figures for BIA education (.898) and Indian education programs (.713) show that both have fallen consistently over the time period.

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[2] Budget functions represent classifications of budget expenditures by major objectives and operations, regardless of the agency responsible.

Table 4 compares budget trends in constant dollars during the years of the Reagan and Bush administrations (FY1982-1991). The Department of Education has averaged $15.5 billion with an increase of $345.7 million (2.23 percent) a year. BIA education, on the other hand, has declined $6.5 million (-2.75 percent) a year, and Indian education in the Education Department has fallen $2 million (3.36 percent) a year. All these trends are about equally consistent.

Graphs 1-3 illustrate the trends in constant dollars for FY1975-1991. Graph 1 shows the generally upward, but fluctuating, trend for the Department of Education budget. Graphs 2 and 3 show the long-term downward trends for BIA education and Indian education in the Department of Education.

## HEALTH

Federal health outlays (i.e., the health budget function), as shown in table 2, averaged $30.9 billion in constant 1982 dollars during FY1975-1991, increasing at a rate of $1.3 billion a year, for a change ratio of 4.09 percent. Expenditures of the Department of Health and Human Services (HHS), which include more than health spending, averaged $108.1 billion in the same time period, increasing at $5.1 billion (4.76 percent) a year. Indian Health Service appropriations, in constant dollars, also increased during FY1975-1991, but at lower rate: its annual increase was $19.7 million, or 2.58 percent, on an average level of $763.8 million.

Spending on the health budget function during the Reagan and Bush administrations, shown in table 4, was at an average level of $34.5 billion in constant dollars during FY1982-1991, with an annual increase of 2.2 billion (6.37 percent). HHS outlays averaged 126.7 billion, increasing $4.8 billion (3.82 percent) annually. IHS spending showed lesser gains during the same period, receiving annual increases of $28.6 million per year, or 3.53 percent, on an average level of $811.1 million.

Graphs 4-6 depict the trends in the HHS, health function, and IHS budgets for the years FY1975-1991, in constant dollars. They show that the increase over time was more consistent for HHS ($r^2$ of .975) and the Federal health function ($r^2$ of .839) than for IHS ($r^2$ of .625).

## HOUSING AND ECONOMIC DEVELOPMENT

Housing expenditures for the entire U.S. and for Indians have been significantly different. Table 2 shows that the Department of Housing and Urban Development budget averaged $14.6 billion in constant dollars from FY1978 to FY1991[3] and increased at an annual rate of $401.1 million, for a change ratio of 2.74 percent. Indian housing, on the other hand, decreased at an annual rate of $36 million, or -9.18 percent, with an average level of $392.1 million. Graph 7 illustrates the HUD trend and Graph 8 depicts the trend for Indian housing. Graph 9 combines the two sets of data.

Housing trends in the Reagan and Bush administrations (FY1982-1991) have fallen below those for the longer period. Indian housing has decreased at an annual rate of $45.7 million (-19.99 percent) on an average level of $228.7 million, while overall HUD spending has remained almost flat, growing by only $5.9 million (0.04 percent) a year on an average level of $16.3 billion.

Economic development has not fared well during the period FY1975-1991 in either the overall U.S. budget or the Indian-related budget. Here we compare the overall U.S. economic development budget function with the BIA economic development program and with the Administration for Native Americans, which provides funding for social and economic development projects to Indian tribal governments and non-governmental Indian organizations.

All three economic development programs have lost ground in constant dollars, but the Indian-related ones have fallen faster. Table 2 shows that the U.S. economic development function has declined at an annual rate of $464.2 million, for a change ratio of -5.56 percent, while averaging $8.3 billion a year in spending during this period. ANA expenditures, with an average level of $34.3 million, have decreased by $2.3 million, or -6.59 percent, a year. The BIA economic development program has lost the most, falling by $4.9 million, or -7.59 percent, a year (on an average level of $64.1 million). Graphs 10-12, and the respective $r^2$'s for the economic development function (.454), BIA economic development (.767), and ANA (.805), all show that the decline has been most consistent over the time period for the Indian-related programs.

Economic development spending during the Reagan and Bush administrations (FY1982-1991) has continued to decline, as shown in table 4. The Federal economic development function during this period fell faster than ANA, dwindling by $312.3 million (-5.09 percent) a year on average spending of $6.1 billion. ANA fell only by -1.97 percent ($0.5 million) a year on an average level of $25.3 million. BIA economic development went down the fastest, being reduced by -8.55 percent ($3.8 million) a year on average spending of $44.2 million. Again the downward trends were more consistent for the Indian-related items than for the overall Federal economic development function.

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[3] The time period for housing data is shortened from FY1975-1991 to FY1978-1991 because of missing data for Indian housing in FY1977.

## OVERALL BUDGET AREAS

This section compares trends over the time period for the total BIA budget, overall Indian-related spending, and the Federal non-defense budget[4] as a whole, using both current and constant dollars. For the BIA, table 1 and graph 13 display an increase in spending in current dollars, with spending going up by $24.9 million (change ratio of 2.45 percent) a year with an average level of $1 billion. Table 2 and graph 14, however, show that in constant dollars there was actually a decline in the BIA budget of $27.8 million (-2.64 percent) a year, on an average level of $1.1 billion. A reasonably steady increase ($r^2$ of .669) in current dollars becomes, when corrected for inflation, an equally steady decline ($r^2$ of 726) in constant dollars.

Federal non-defense spending as a whole exhibits a departure from the pattern for Indian-related spending, however. Federal spending as a whole in current dollars went up during the period FY1975-1991, at a rate of $32.2 billion (6.62 percent) with an average level of $487 billion (see table 1). In constant dollars, Federal spending still went up, at a rate of $9.6 billion (2.01 percent) on an average level of $479 billion (see table 2). Graphs 15 and 16 illustrate these upward trends in current and constant dollars.

The overall Indian-related budget returns to the same pattern as the BIA. Current-dollar spending during the FY1975-1991 period, as shown in table 1, went up at a rate of $59.3 million, or 2.64 percent, a year, on an average level of $2.2 billion. Constant-dollar spending, however, is shown in table 2 to have gone down at a rate of $48.8 million, or -2.11 percent, a year, with an average level of $2.3 billion. Graphs 17 and 18 demonstrate the two trends.

Population data can be used to get a simple comparison of per-capita Federal spending between the overall U.S. population and the Indian population. Table 1 includes population data similar to the budget data. The data (which include projections) show that the overall U.S. population increased at a rate of 2,264,718 million people (0.97 percent) a year during the period 1975-1991, with an average level of 234,292,824 million people. The Indian population (as measured by the IHS service population) is much smaller, with an average level of 885,751, but it has grown much faster, increasing at an annual rate of 33,593, or 3.79 percent. To get a measure of per-capita Federal spending for each of the two groups, we took each year in the FY1975-1991 period and divided the Federal non-defense budget by the total U.S. population, and the overall Indian budget by the Indian population. We used current dollars for this measure.

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[4] The Federal non-defense budget used here excludes both national defense expenditures and net interest payments on the national debt.

Graph 19 illustrates the resulting trends. It shows that during the first ten years of the period the Federal government spent more per capita on Indians than on the population as a whole. After 1985, however, Indians received less expenditure per capita than the population as a whole. Throughout the 1975-1991 period, per-capita spending on the population as a whole consistently increased, whereas per-capita spending on Indians began to fall in 1979, with no significant upward change until 1990.

## SUMMARY

The data show that Indian-related spending, corrected for inflation, has been going down in almost all areas. Among the Indian-related items examined, only Indian health and BIA natural resources spending have avoided this trend. (BIA Indian services spending has been flat.)

This downward trend is not obvious if one looks only at current-dollar data. One has to look instead at constant-dollar figures. The tables and graphs show that, in constant dollars, overall Indian spending has gone down, while overall Federal non-defense spending has gone up.

When one looks not only at overall Indian spending but also at its major parts -- BIA, IHS, Indian education in the Education Department, Indian housing in HUD, and ANA -- one sees from table 2 and graph 20 that, in constant dollars, all major spending items except IHS have declined during the period FY1975-1991. Moreover, a comparison in constant dollars of overall Indian spending and its major parts, on the one hand, to comparable budget items in the full Federal budget, on the other, indicates that all Indian-related spending areas have lagged behind their equivalent Federal spending areas. (See graph 21.) This is true even of IHS.

If the BIA budget and overall Indian spending were to decline at the same rates of annual change during the period FY1992-2000 as they did during FY1975-1991 (-$27.8 million and -$48.8 million, respectively, in constant dollars), as shown in graph 22, then by FY2000 overall Indian-related spending would have fallen below $1.5 billion in 1982 dollars, and BIA spending would have diminished to less than $621 million in 1982 dollars.

If you have any questions, or if I can be of further assistance, please call me at 707-8641.

Attachments

Table 1. TRENDS IN SELECTED ELEMENTS OF THE FEDERAL BUDGET in CURRENT DOLLARS, FY1975-1991

[Dollar figures in millions]

| | Average Level | Annual Change | Change Ratio* | $r^2$ |
|---|---|---|---|---|
| **Education:** | | | | |
| U.S. Dept of Education | $15,334.6 | $913.4 | 5.96% | .915 |
| Education function | $29,215.6 | $1,070.4 | 3.66% | .697 |
| Indian education (U.S. Dept. of Ed.) | $67.2 | $1.0 | 1.43% | .253 |
| BIA education | $264.4 | $2.6 | 1.00% | .372 |
| **Health:** | | | | |
| U.S. Dept. of Health/Hum. Serv. | $113,337.1 | $10,241.6 | 9.04% | .986 |
| Health function | $32,080.3 | $2,817.7 | 8.78% | .932 |
| Indian Health Service | $781.4 | $55.6 | 7.12% | .941 |
| **Housing and Economic Development:** | | | | |
| U.S. Dept. of Housing/Urb. Devt.** | $15,019.2 | $1,060.2 | 7.06% | .703 |
| Indian housing** | $348.6 | -$21.8 | -6.26% | .161 |
| Economic development function | $7,748.6 | -$77.3 | -1.00% | .029 |
| Admin. for Native Americans | $31.4 | -$0.4 | -1.13% | .303 |
| BIA economic development | $58.0 | -$1.8 | -3.06% | .326 |
| **Natural Resources:** | | | | |
| U.S. Dept. of the Interior | $4,403.8 | $186.5 | 4.23% | .856 |
| Fish and Wildlife Service | $349.7 | $21.8 | 6.23% | .908 |
| Bureau of Land Management | $817.8 | $25.6 | 3.13% | .240 |
| Forest Service | $2,088.4 | $103.0 | 4.93% | .910 |
| Natural resources function | $13,010.8 | $515.3 | 3.96% | .830 |
| BIA natural resources | –$100.2 | $7.4 | 7.43% | .809 |
| **Overall:** | | | | |
| BIA Total | $1,012.9 | $24.9 | 2.45% | .669 |
| BIA: Indian services | $226.8 | $10.8 | 4.75% | .810 |
| Overall Indian budget | $2,241.5 | $59.3 | 2.64% | .455 |
| Federal non-defense budget*** | $487,043.4 | $32,242.4 | 6.62% | .989 |
| U.S. population | 234,292,824 | 2,264,718 | .97% | .999 |
| Indian population | 885,751 | 33,593 | 3.79% | .976 |

NOTE: * Annual change as a percent of average level.
** Covers only FY1978-1991.
*** Excludes national defense and net interest payments on national debt.

### Table 2. TRENDS IN SELECTED ELEMENTS OF THE FEDERAL BUDGET in CONSTANT 1982 DOLLARS, FY1975-1991

[Constant dollars based on Implicit Price Deflator for GNP]
[Dollar figures in millions]

| | Average Level | Annual Change | Change Ratio* | $r^2$ |
|---|---|---|---|---|
| **Education:** | | | | |
| U.S. Dept of Education | $15,206.2 | $193.2 | 1.27% | .332 |
| Education function | $29,880.0 | -$378.5 | -1.27% | .180 |
| Indian education (in Dept. of Ed.) | $70.4 | -$2.4 | -3.44% | .713 |
| BIA education | $280.3 | -$11.8 | -4.21% | .898 |
| **Health:** | | | | |
| U.S. Dept. of Health/Hum. Serv. | $108,096.1 | $5,140.5 | 4.76% | .975 |
| Health function | $30,874.2 | $1,262.0 | 4.09% | .839 |
| Indian Health Service | $763.8 | $19.7 | 2.58% | .625 |
| **Housing and Economic Development:** | | | | |
| U.S. Dept. of Housing/Urb. Devt.** | $14,612.1 | $401.1 | 2.74% | .240 |
| Indian housing** | $392.1 | -$36.0 | -9.18% | .246 |
| Economic development function | $8,343.6 | -$464.2 | -5.56% | .454 |
| Admin. for Native Americans | $34.4 | -$2.3 | -6.59% | .805 |
| BIA economic development | $64.1 | -$4.9 | -7.59% | .767 |
| **Natural Resources:** | | | | |
| U.S. Dept. of the Interior | $4,460.7 | -$22.3 | -.50% | .053 |
| Fish and Wildlife Service | $345.6 | $5.7 | 1.66% | .277 |
| Bureau of Land Management | $834.2 | -$11.6 | -1.39% | .065 |
| Forest Service | $2,096.0 | $5.6 | .27% | .019 |
| Natural resources function | $13,257.8 | -$129.5 | -.98% | .202 |
| BIA natural resources | $97.1 | $3.2 | 3.35% | .462 |
| **Overall:** | | | | |
| BIA Total | $1,053.0 | -$27.8 | -2.64% | .726 |
| BIA: Indian services | $228.2 | $.1 | .04% | .000 |
| Overall Indian budget | $2,313.6 | -$48.8 | -2.11% | .285 |
| Federal non-defense budget*** | $478,982.7 | $9,611.1 | 2.01% | .928 |

NOTE: * Annual change as percent of average level
** Covers only 1978-91.
*** Excludes national defense and net interest payments on national debt.

Table 3. TRENDS IN SELECTED ELEMENTS OF THE FEDERAL BUDGET
in CURRENT DOLLARS, FY1982-1991

[Dollar figures in millions]

| | Average Level | Annual Change | Change Ratio* | $r^2$ |
|---|---|---|---|---|
| **Education:** | | | | |
| U.S. Dept of Education | $18,191.3 | $1,022.6 | 5.62% | .904 |
| Education function | $31,814.4 | $1,548.8 | 4.87% | .891 |
| Indian education (U.S. Dept. of Ed.) | $69.7 | $.1 | .14% | .004 |
| BIA education | $272.8 | $1.9 | .70% | .072 |
| **Health:** | | | | |
| U.S. Dept. of Health/Hum. Serv. | $149,592.1 | $10,629.2 | 7.11% | .963 |
| Health function | $41,034.6 | $3,983.4 | 9.71% | .938 |
| Indian Health Service | $957.0 | $65.6 | 6.86% | .952 |
| **Housing and Economic Development:** | | | | |
| U.S. Dept. of Housing/Urb. Devt.** | $19,049.5 | $643.1 | 3.38% | .178 |
| Indian housing** | $252.4 | -$44.8 | -17.74% | .904 |
| Economic development function | $7,080.0 | -$103.6 | -1.46% | .054 |
| Admin. for Native Americans | $29.4 | $.4 | 1.39% | .758 |
| BIA economic development | $50.4 | -$2.8 | -5.49% | .493 |
| **Natural Resources:** | | | | |
| U.S. Dept. of the Interior | $5,000.1 | $165.3 | 3.31% | .855 |
| Fish and Wildlife Service | $421.5 | $22.5 | 5.35% | .858 |
| Bureau of Land Management | $901.7 | $.5 | .06% | .000 |
| Forest Service | $2,425.9 | $91.9 | 3.79% | .935 |
| Natural resources function | $14,507.7 | $616.6 | 4.25% | .828 |
| BIA natural resources | $127.9 | $5.1 | 3.95% | .331 |
| **Overall:** | | | | |
| BIA Total | $1,086.4 | $26.7 | 2.45% | .440 |
| BIA: Indian services | $263.8 | $8.4 | 3.18% | .439 |
| Overall Indian budget | $2,395.0 | $48.0 | 2.01% | .574 |
| Federal non-defense budget*** | $599,996.1 | $30,368.4 | 5.06% | .962 |
| U.S. population | 242,319,600 | 2,120,897 | .88% | .999 |
| Indian population | 1,002,873 | 28,791 | 2.87% | .998 |

NOTE: * Annual change as percent of average level.
** Covers only 1978-91.
*** Excludes national defense and net interest payments on national debt.

## Table 4. TRENDS IN SELECTED ELEMENTS OF THE FEDERAL BUDGET in CONSTANT 1982 DOLLARS, FY1982-1991

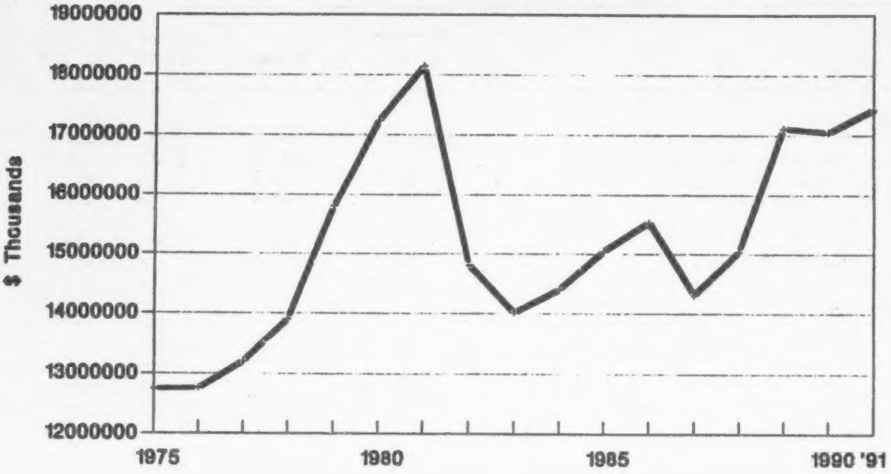
[Constant dollars based on Implicit Price Deflator for GNP]
[Dollar figures in millions]

| | Average Level | Annual Change | Change Ratio* | $r^2$ |
|---|---|---|---|---|
| **Education:** | | | | |
| U.S. Dept of Education | $15,471.7 | $345.7 | 2.23% | .686 |
| Education function | $27,115.2 | $394.9 | 1.46% | .528 |
| Indian education (in Dept. of Ed.) | $60.2 | -$2.0 | -3.36% | .656 |
| BIA education | $235.2 | -$6.5 | -2.75% | .561 |
| **Health:** | | | | |
| U.S. Dept. of Health/Hum. Serv. | $126,698.1 | $4,835.1 | 3.82% | .901 |
| Health function | $34,506.7 | $2,196.7 | 6.37% | .931 |
| Indian Health Service | $811.1 | $28.6 | 3.53% | .911 |
| **Housing and Economic Development:** | | | | |
| U.S. Dept. of Housing/Urb. Devt.** | $16,295.8 | $5.9 | .04% | .000 |
| Indian housing** | $228.7 | -$45.7 | -19.99% | .927 |
| Economic development function | $6,139.1 | -$312.3 | -5.09% | .438 |
| Admin. for Native Americans | $25.3 | -$0.5 | -1.97% | .892 |
| BIA economic development | $44.2 | -$3.8 | -8.55% | .711 |
| **Natural Resources:** | | | | |
| U.S. Dept. of the Interior | $4,279.4 | $.6 | .01% | .000 |
| Fish and Wildlife Service | $358.7 | $7.2 | 2.01% | .494 |
| Bureau of Land Management | $779.0 | -$30.2 | -3.88% | .151 |
| Forest Service | $2,073.7 | $10.4 | .50% | .183 |
| Natural resources function | $12,386.4 | $98.9 | .80% | .185 |
| BIA natural resources | $109.3 | $1.1 | .97% | .029 |
| **Overall:** | | | | |
| BIA Total | $932.2 | -$9.1 | -.97% | .116 |
| BIA: Indian services | $225.9 | -$0.6 | -.25% | .005 |
| Overall Indian budget | $2,057.4 | -$28.7 | -1.39% | .443 |
| Federal non-defense budget*** | $511,085.1 | $8,762.3 | 1.71% | .858 |

NOTE: * Annual change as percent of average level.
** Covers only 1978-91.
*** Excludes national defense and net interest payments on national debt.

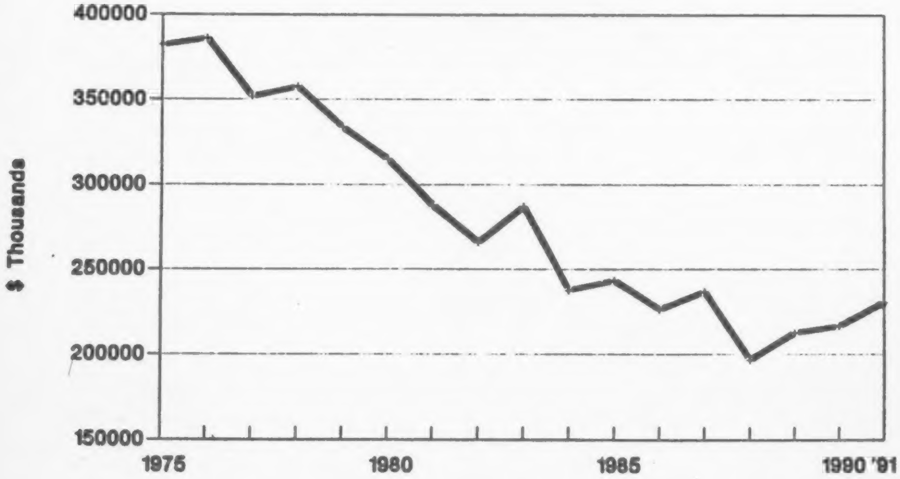
## Graph 1
## U.S. Education Dept. Budget, FY1975-91

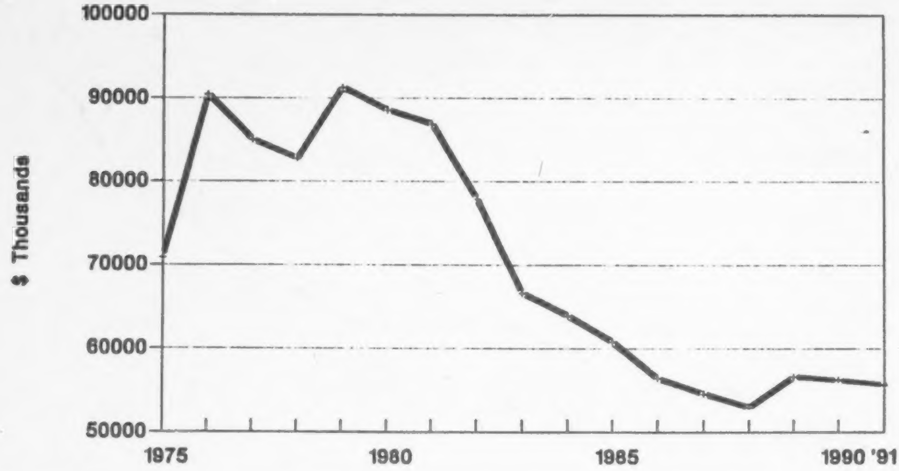
**In Constant 1982 Dollars**



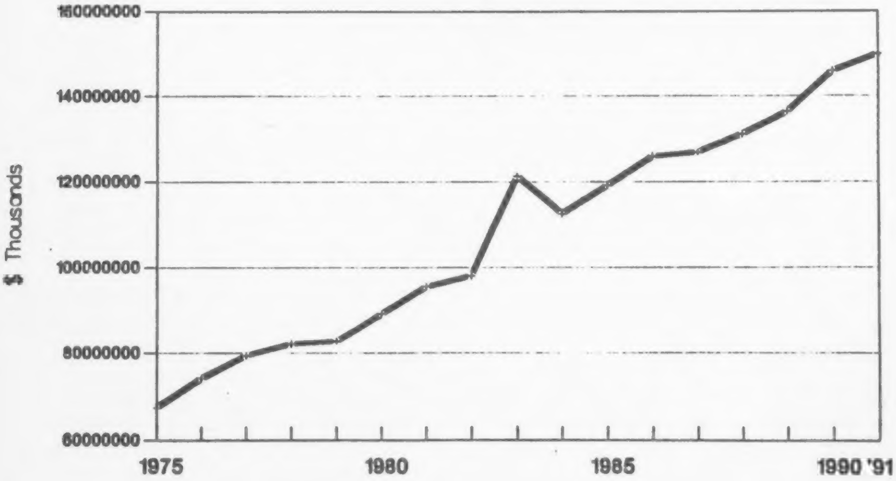
## Graph 2
## BIA Education Budget, FY1975-91

**In Constant 1982 Dollars**





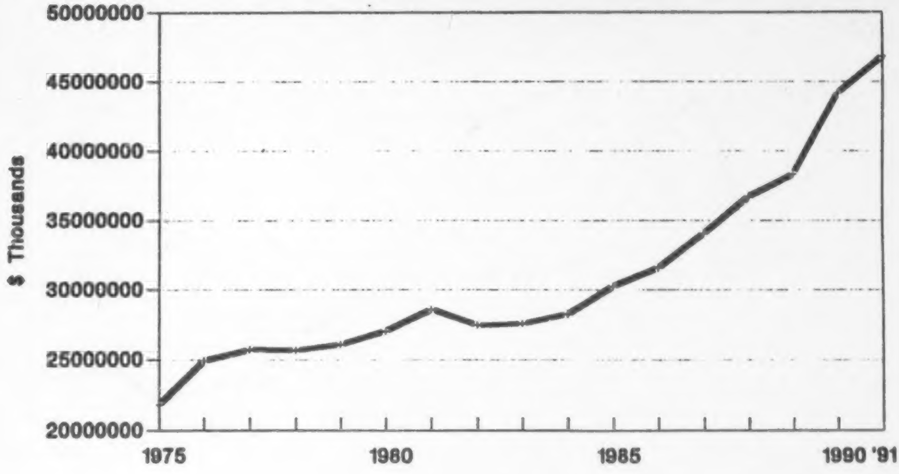
**Graph 3**
**Indian Education in Educ. Dept., FY1975-91**
**In Constant 1982 Dollars**



**Graph 4**
**U.S. HHS Dept. Budget, FY1975-91**
**In Constant 1982 Dollars**

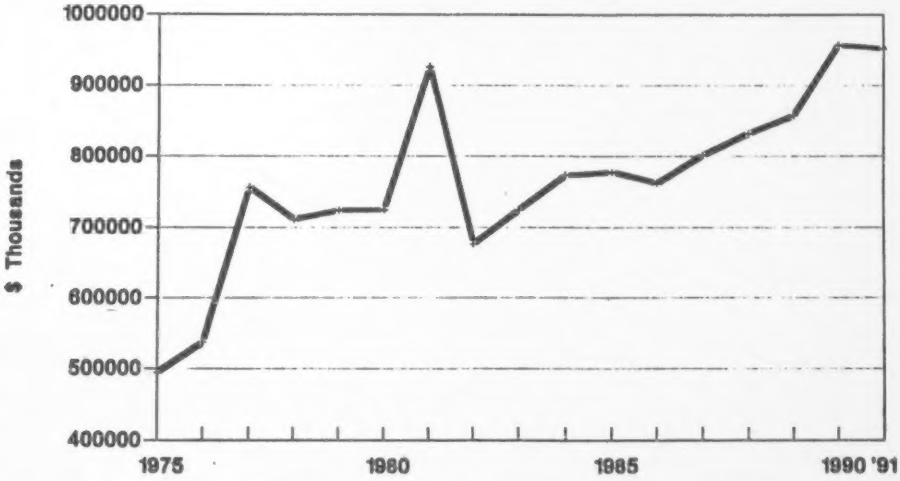
## Graph 5
## U.S. Health Function Spending, FY1975-91

In Constant 1982 Dollars



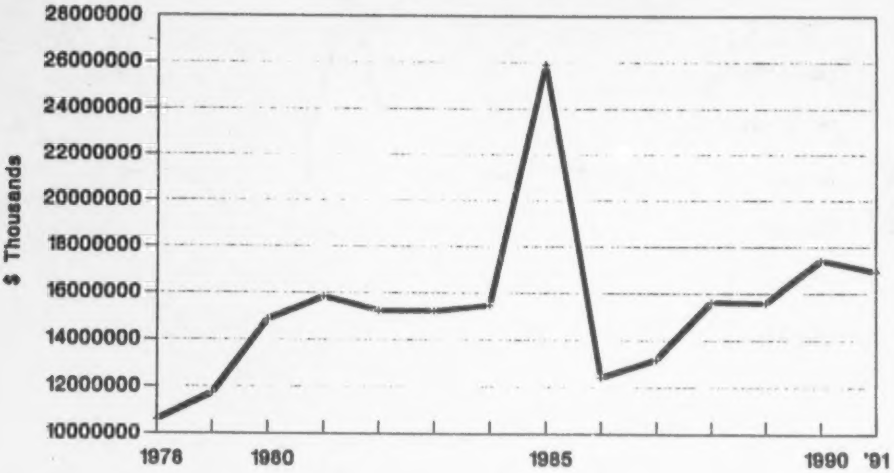
## Graph 6
## Indian Health Service Budget, FY1975-91

In Constant 1982 Dollars



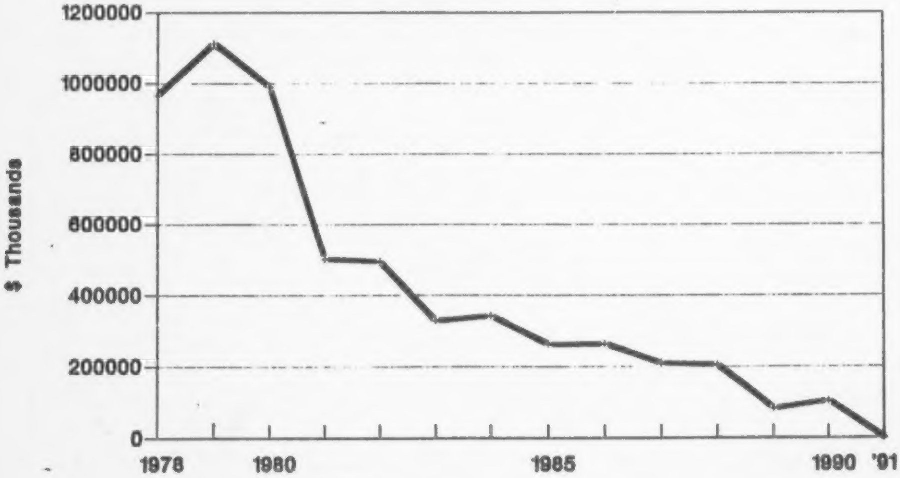
## Graph 7
## U.S. HUD Dept. Budget, FY1978-91

**In Constant 1982 Dollars**

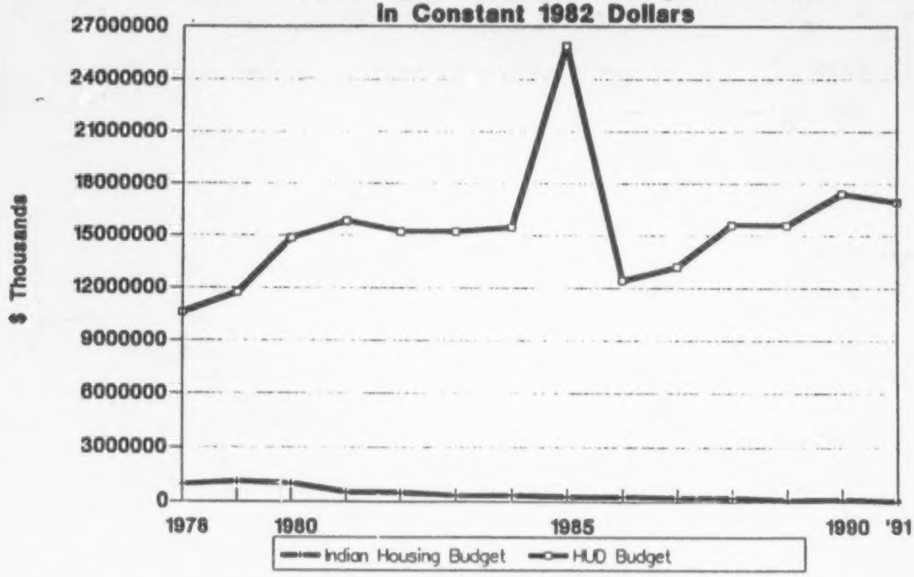


## Graph 8
## Indian Housing Budget In HUD, FY1978-91

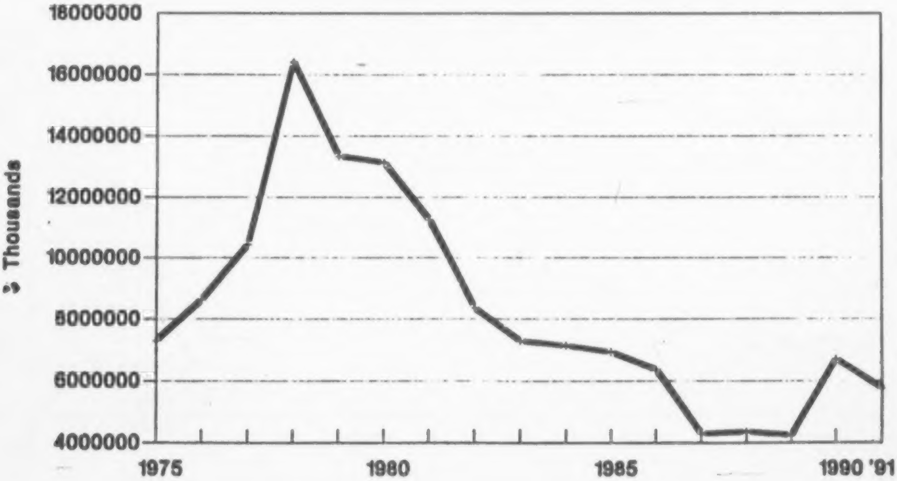
**In Constant 1982 Dollars**



## Graph 9
## Indian Housing vs. HUD Budget, FY1978-91
In Constant 1982 Dollars

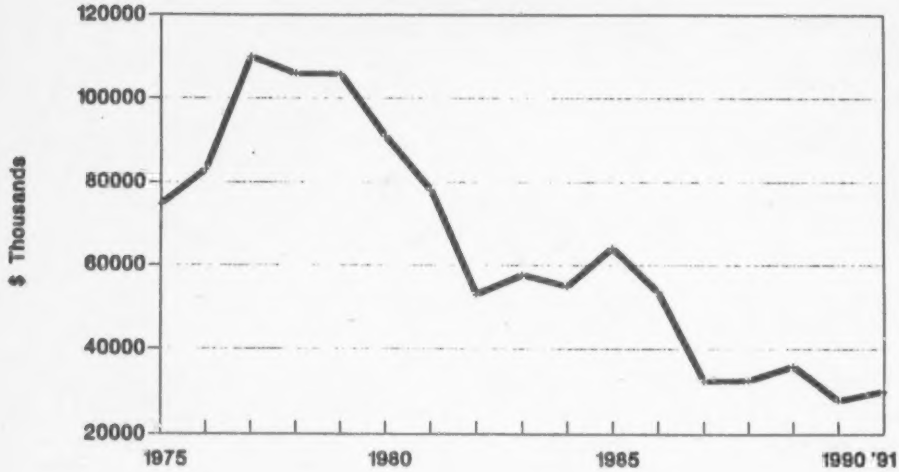


## Graph 10
## U.S. Economic Devt. Function, FY75-91
In Constant 1982 Dollars



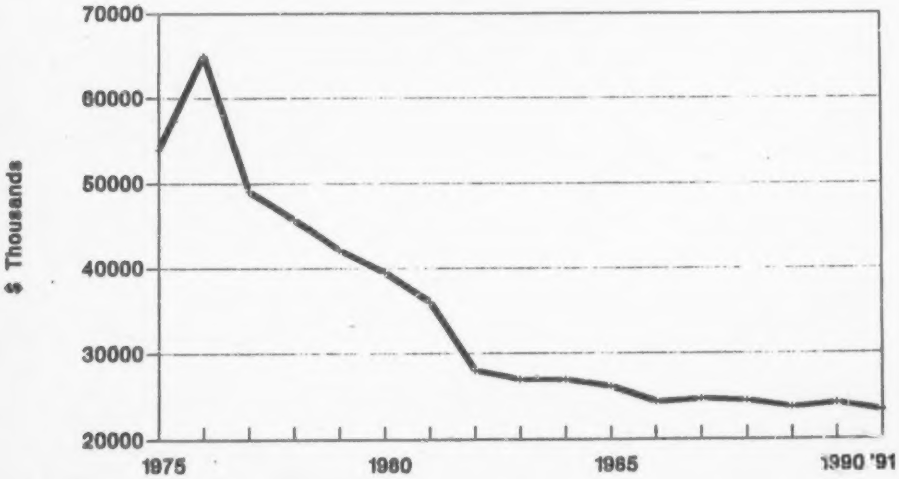
## Graph 11
## BIA Economic Development Budget, FY75-91

In Constant 1982 Dollars



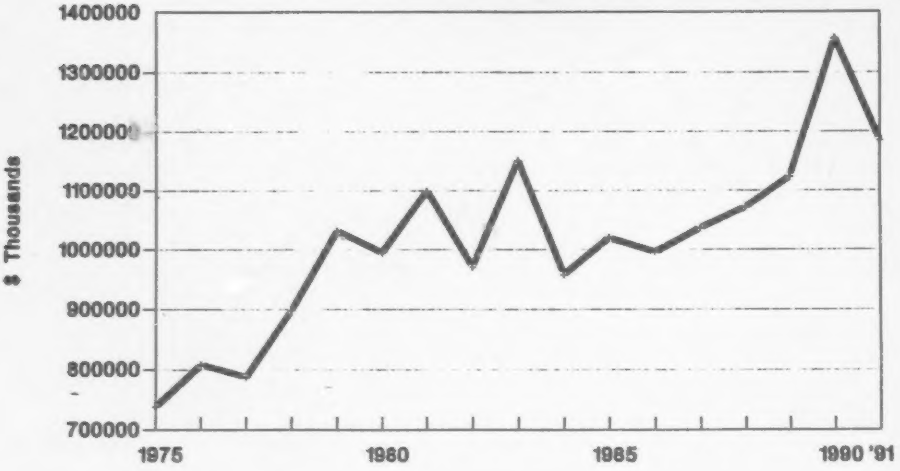
## Graph 12
## ANA Budget, FY1975-91

In Constant 1982 Dollars



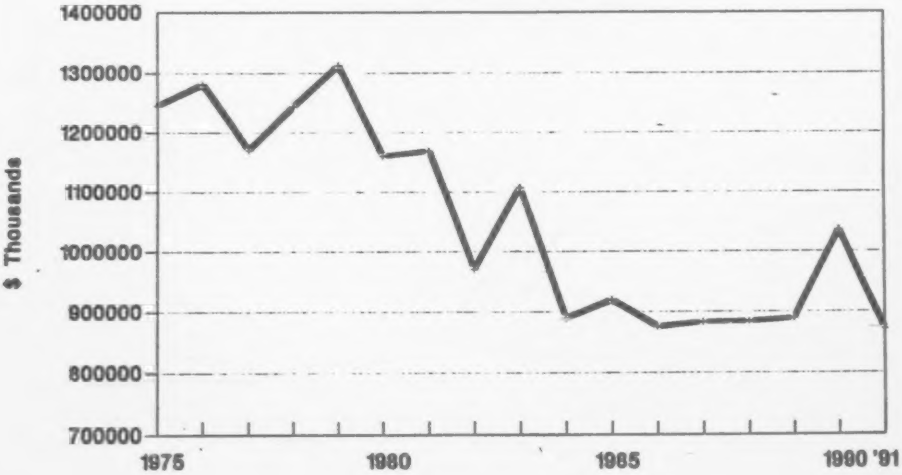
## Graph 13
## BIA Total Budget, FY1975-91

In Current Dollars



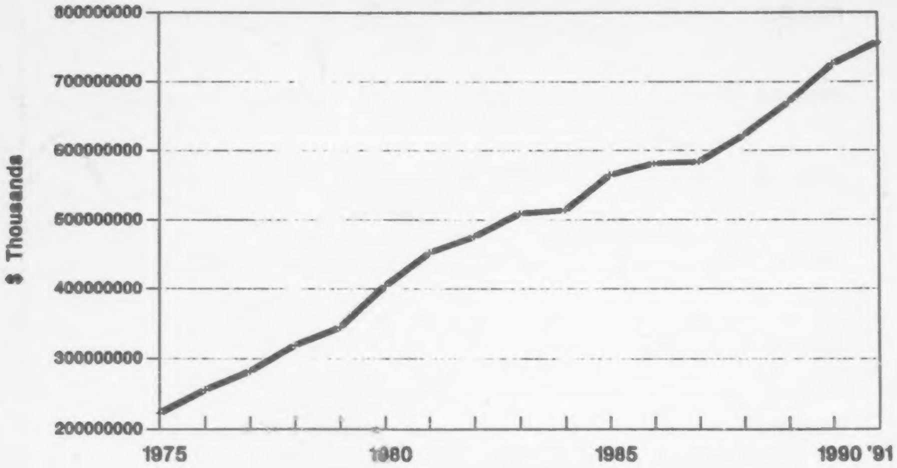
## Graph 14
## BIA Total Budget, FY1975-91

In Constant 1982 Dollars



## Graph 15
## Overall Federal Govt. Budget*, FY75-91

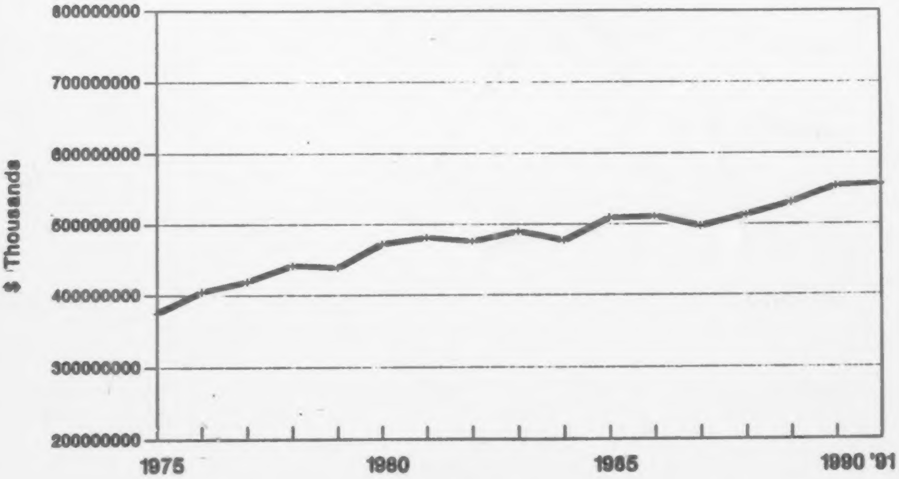
**In Current Dollars**



* Excluding Defense and Net Interest

## Graph 16
## Overall Federal Govt. Budget*, FY75-91

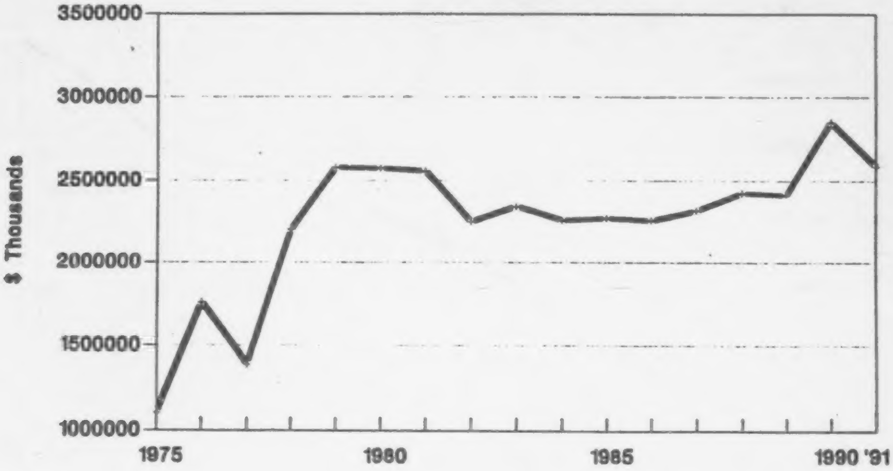
**In Constant 1982 Dollars**



* Excluding Defense and Net Interest

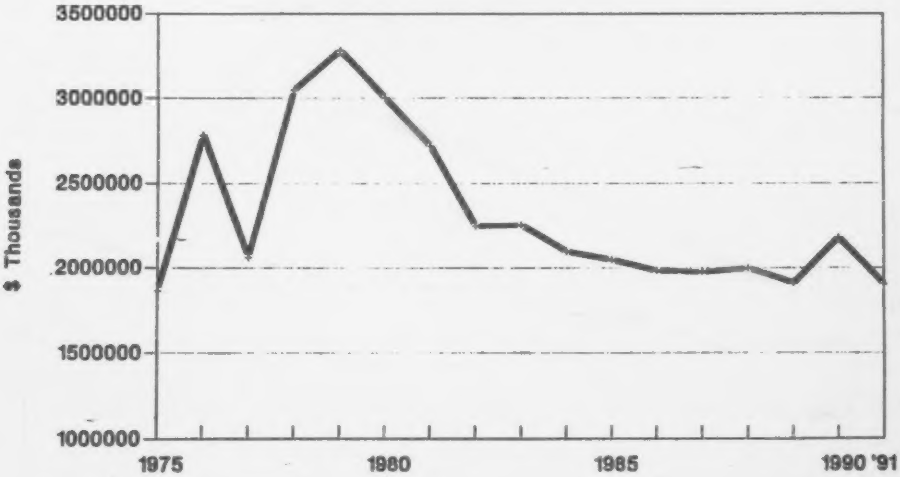
## Graph 17
## Overall Indian Budget, FY1975-91

**In Current Dollars**



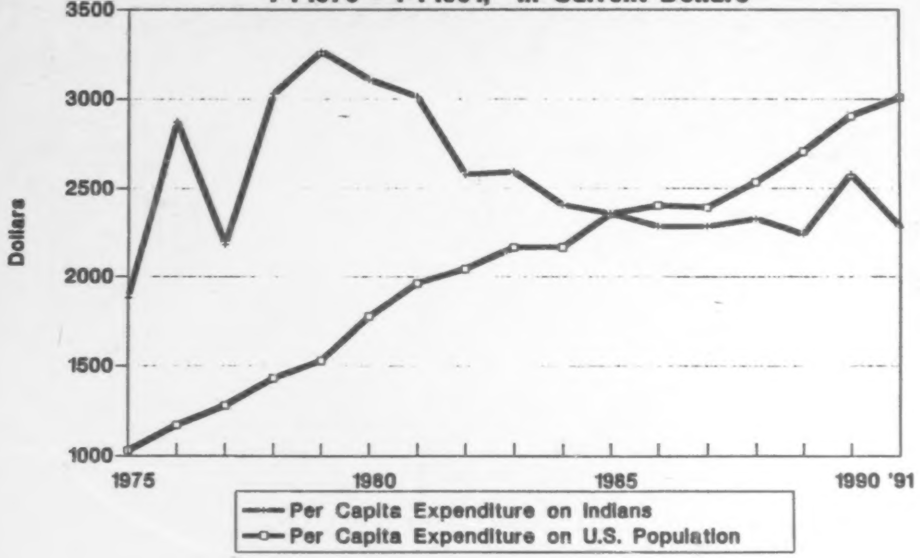
## Graph 18
## Overall Indian Budget, FY1975-91

**In Constant 1982 Dollars**

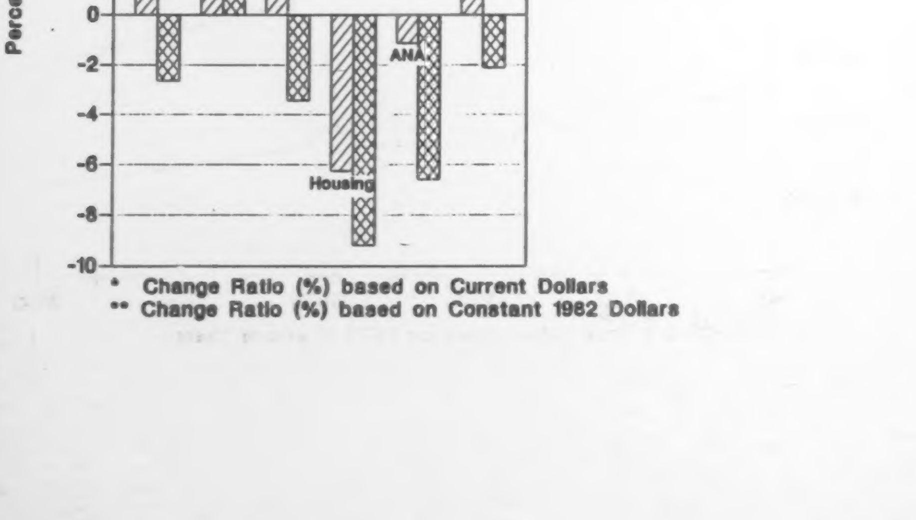


## Graph 19
## Per Capita Expenditure: US Pop. & Indian Pop

**FY1975 - FY1991, In Current Dollars**

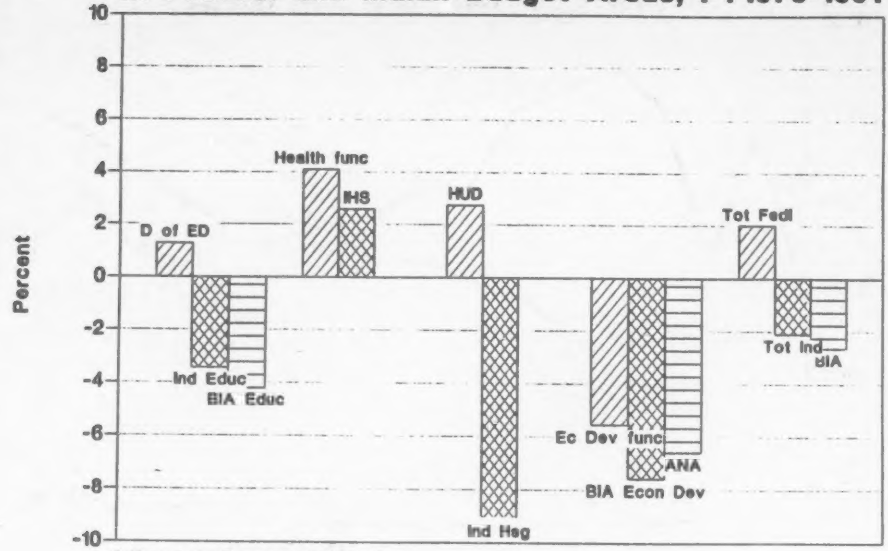


## Graph 20
## Apparent Vs. Real Change Ratios In Indian Budget Areas, FY1975-1991



* Change Ratio (%) based on Current Dollars
** Change Ratio (%) based on Constant 1982 Dollars

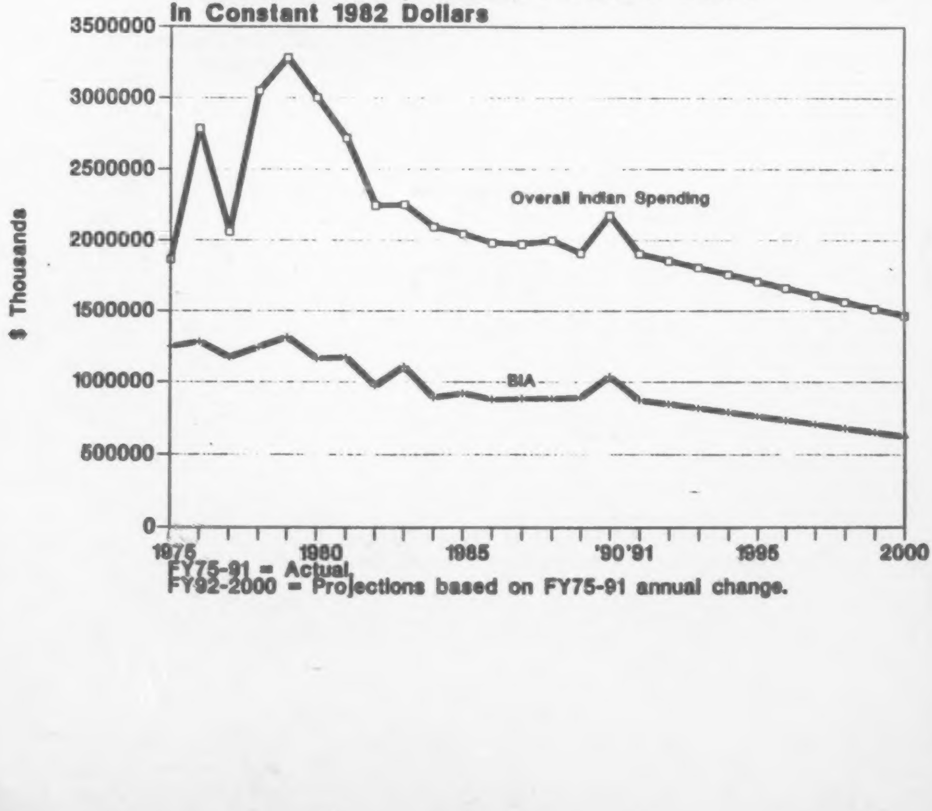
## Graph 21
## Comparison of Real* Change Ratios (in Percent) in Federal and Indian Budget Areas, FY1975-1991



* Based on Constant 1982 Dollars.

## Graph 22: BIA & Overall Indian Spending, Actual & Projected, FY1975-2000

In Constant 1982 Dollars



FY75-91 = Actual.
FY92-2000 = Projections based on FY75-91 annual change.

### Appendix Table 1. Budget Data for Selected Elements of the Federal Budget, in Current Dollars, FY1975-1991

[Dollar amounts in thousands, except per-capita figures]

| Fiscal Year | Bureau of Indian Affairs (Approps.) | Indian Health Service (Approps.) | Indian Education in Dept. of Educ. (Approps.) | Indian Housing in HUD (B.A. Use) | Admin. for Native Americans (Approps.) | Overall Indian Budget |
|---|---|---|---|---|---|---|
| 1975 | $738,236 | $293,103 | $42,034 | N/A | $32,000 | $1,105,373 |
| 1976 | $808,095 | $338,926 | $57,055 | $511,200 | $41,000 | $1,756,276 |
| 1977 | $787,359 | $509,055 | $57,212 | N/A | $33,000 | $1,386,626 |
| 1978 | $897,740 | $513,267 | $59,732 | $696,900 | $33,000 | $2,200,639 |
| 1979 | $1,031,195 | $569,153 | $71,735 | $874,300 | $33,100 | $2,579,483 |
| 1980 | $994,227 | $620,871 | $75,900 | $847,900 | $33,800 | $2,572,698 |
| 1981 | $1,098,447 | $869,762 | $81,680 | $471,500 | $33,800 | $2,555,189 |
| 1982 | $970,360 | $676,157 | $77,852 | $494,300 | $28,000 | $2,246,669 |
| 1983 | $1,149,902 | $752,916 | $69,185 | $340,600 | $28,000 | $2,340,603 |
| 1984 | $957,593 | $832,407 | $68,780 | $368,100 | $29,000 | $2,255,880 |
| 1985 | $1,019,411 | $862,203 | $67,404 | $290,200 | $29,000 | $2,268,218 |
| 1986 | $995,693 | $867,177 | $64,187 | $299,500 | $27,742 | $2,254,299 |
| 1987 | $1,036,253 | $940,750 | $64,036 | $245,000 | $28,989 | $2,315,028 |
| 1988 | $1,071,406 | $1,008,818 | $64,234 | $247,800 | $29,679 | $2,421,937 |
| 1989 | $1,122,966 | $1,081,993 | $71,553 | $102,699 | $29,975 | $2,409,186 |
| 1990E | $1,355,720 | $1,252,970 | $73,620 | $136,099 | $31,711 | $2,850,120 |
| 1991P | $1,185,178 | $1,295,080 | $75,762 | $0 | $31,711 | $2,587,731 |

| Fiscal Year | BIA Education Program (Approps.) | BIA Indian Services Program* (Approps.) | BIA Economic Devt. Program** (Approps.) | BIA Natural Resources Program (Approps.) | U.S. Dept. of Education (Outlays) | U.S. Dept. of HHS (Outlays) |
|---|---|---|---|---|---|---|
| 1975 | $226,495 | $98,703 | $44,223 | $31,337 | $7,557,000 | $39,997,000 |
| 1976 | $243,590 | $137,616 | $52,441 | $36,012 | $8,049,000 | $46,834,000 |
| 1977 | $236,700 | $159,118 | $73,966 | $45,536 | $8,887,000 | $53,464,000 |
| 1978 | $258,203 | $189,086 | $76,422 | $76,967 | $10,037,000 | $59,329,000 |
| 1979 | $262,242 | $205,198 | $83,162 | $75,338 | $12,423,000 | $65,038,000 |
| 1980 | $270,033 | $201,128 | $77,971 | $74,237 | $14,770,000 | $76,374,000 |
| 1981 | $270,183 | $227,249 | $73,365 | $85,711 | $17,053,000 | $89,774,000 |
| 1982 | $265,606 | $235,315 | $52,884 | $84,743 | $14,808,000 | $98,020,000 |
| 1983 | $298,143 | $277,865 | $59,821 | $119,241 | $14,558,000 | $125,941,000 |
| 1984 | $255,754 | $231,355 | $59,009 | $99,657 | $15,511,000 | $121,082,000 |
| 1985 | $269,644 | $219,071 | $71,002 | $124,101 | $16,682,000 | $132,104,000 |
| 1986 | $257,299 | $211,588 | $60,810 | $135,179 | $17,673,000 | $143,253,000 |
| 1987 | $277,783 | $252,761 | $38,025 | $144,428 | $16,800,000 | $148,893,000 |
| 1988 | $238,434 | $317,198 | $39,543 | $146,010 | $18,246,000 | $159,071,000 |
| 1989 | $268,503 | $293,150 | $45,299 | $181,696 | $21,608,000 | $172,301,000 |
| 1990E | $283,486 | $296,093 | $36,496 | $124,014 | $22,316,000 | $191,174,000 |
| 1991P | $313,290 | $303,208 | $40,953 | $119,831 | $23,711,000 | $204,082,000 |

See notes at end of table.

Appendix Table 1. Budget Data for Selected Elements of the Federal Budget, in Current Dollars, FY1975-1991 -- Continued

[Dollar amounts in thousands, except per-capita figures]

| Fiscal Year | U.S. Dept. of HUD (Outlays) | U.S. Dept. of Interior (Outlays) | Education Function (Outlays) | Health Function (Outlays) | Economic Development Function (Outlays) |
|---|---|---|---|---|---|
| 1975 | $7,512,000 | $2,223,000 | $16,022,000 | $12,930,000 | $4,322,000 |
| 1976 | $7,026,000 | $2,435,000 | $18,910,000 | $15,734,000 | $5,442,000 |
| 1977 | $5,808,000 | $3,216,000 | $21,104,000 | $17,302,000 | $7,021,000 |
| 1978 | $7,650,000 | $3,878,000 | $26,710,000 | $18,524,000 | $11,841,000 |
| 1979 | $9,220,000 | $4,174,000 | $30,223,000 | $20,494,000 | $10,480,000 |
| 1980 | $12,735,000 | $4,477,000 | $31,843,000 | $23,169,000 | $11,252,000 |
| 1981 | $14,880,000 | $4,461,000 | $33,709,000 | $26,866,000 | $10,568,000 |
| 1982 | $15,232,000 | $3,948,000 | $27,029,000 | $27,445,000 | $8,347,000 |
| 1983 | $15,814,000 | $4,552,000 | $26,606,000 | $28,641,000 | $7,560,000 |
| 1984 | $16,663,000 | $4,947,000 | $27,579,000 | $30,417,000 | $7,673,000 |
| 1985 | $28,720,000 | $4,825,000 | $29,342,000 | $33,542,000 | $7,680,000 |
| 1986 | $14,139,000 | $4,789,000 | $30,585,000 | $35,936,000 | $7,233,000 |
| 1987 | $15,484,000 | $5,050,000 | $29,724,000 | $39,968,000 | $5,051,000 |
| 1988 | $18,938,000 | $5,147,000 | $31,938,000 | $44,490,000 | $5,294,000 |
| 1989 | $19,680,000 | $5,213,000 | $36,684,000 | $48,390,000 | $5,361,000 |
| 1990E | $22,802,000 | $5,832,000 | $37,652,000 | $57,819,000 | $8,776,000 |
| 1991P | $23,023,000 | $5,698,000 | $41,005,000 | $63,698,000 | $7,825,000 |

| Fiscal Year | Natural Resources Function (Outlays) | U.S. Forest Service (Approps.) | U.S. Fish & Wildlife Service (Approps.) | Bureau of Land Management (Approps.) | Total Federal Non-Defense Budget*** (Outlays) |
|---|---|---|---|---|---|
| 1975 | $7,346,000 | $1,032,627 | $128,695 | $398,892 | $222,579,000 |
| 1976 | $8,184,000 | $1,041,911 | $156,986 | $425,670 | $255,446,000 |
| 1977 | $10,032,000 | $1,381,031 | $215,712 | $477,513 | $282,076,000 |
| 1978 | $10,983,000 | $1,743,837 | $287,030 | $778,783 | $318,793,000 |
| 1979 | $12,135,000 | $1,883,000 | $341,725 | $845,929 | $344,507,000 |
| 1980 | $13,858,000 | $2,049,802 | $299,448 | $926,720 | $404,413,000 |
| 1981 | $13,568,000 | $2,112,684 | $300,097 | $1,032,942 | $451,962,000 |
| 1982 | $12,998,000 | $1,992,050 | $329,516 | $1,232,512 | $475,402,000 |
| 1983 | $12,672,000 | $2,131,500 | $329,642 | $1,109,262 | $508,650,000 |
| 1984 | $12,593,000 | $2,165,926 | $376,522 | $653,251 | $513,310,000 |
| 1985 | $13,357,000 | $2,268,483 | $433,825 | $844,705 | $564,138,000 |
| 1986 | $13,639,000 | $2,473,708 | $367,541 | $564,154 | $580,914,000 |
| 1987 | $13,363,000 | $2,365,020 | $426,036 | $692,159 | $583,261,000 |
| 1988 | $14,606,000 | $2,553,102 | $426,055 | $774,904 | $621,935,000 |
| 1989 | $16,182,000 | $2,780,203 | $456,696 | $871,612 | $669,947,000 |
| 1990E | $17,499,000 | $2,784,137 | $533,506 | $1,266,491 | $725,303,000 |
| 1991P | $18,168,000 | $2,744,540 | $535,661 | $1,007,833 | $757,101,000 |

See notes at end of table.

**Appendix Table 1. Budget Data for Selected Elements of the Federal Budget, in Current Dollars, FY1975-1991 -- Continued**

**[Dollar amounts in thousands, except per-capita figures]**

| Fiscal Year | U.S. Population | Indian Population (IHS data) | Overall U.S. Per Capita Expenditure | Indian Per Capita Expenditure | Implicit Price Deflator for GNP (1982=100) |
|---|---|---|---|---|---|
| 1975 | 215,973,000 | 587,468 | $1,031 | $1,882 | 59.3 |
| 1976 | 218,035,000 | 611,296 | $1,172 | $2,873 | 63.1 |
| 1977 | 220,239,000 | 635,313 | $1,281 | $2,183 | 67.3 |
| 1978 | 222,585,000 | 726,551 | $1,432 | $3,029 | 72.2 |
| 1979 | 225,055,000 | 790,486 | $1,531 | $3,263 | 78.6 |
| 1980 | 227,757,000 | 828,609 | $1,776 | $3,105 | 85.7 |
| 1981 | 230,138,000 | 849,315 | $1,964 | $3,009 | 94.0 |
| 1982 | 232,520,000 | 870,963 | $2,045 | $2,580 | 100.0 |
| 1983 | 234,799,000 | 902,627 | $2,166 | $2,593 | 103.9 |
| 1984 | 237,001,000 | 937,043 | $2,166 | $2,407 | 107.7 |
| 1985 | 239,283,000 | 961,884 | $2,358 | $2,358 | 110.9 |
| 1986 | 241,596,000 | 986,881 | $2,404 | $2,284 | 113.8 |
| 1987 | 243,773,000 | 1,012,872 | $2,393 | $2,286 | 117.4 |
| 1988 | 245,302,000 | 1,039,841 | $2,535 | $2,329 | 121.3 |
| 1989 | 247,498,000 | 1,076,417 | $2,707 | $2,238 | 126.3 |
| 1990E | 249,657,000 | 1,105,486 | $2,905 | $2,578 | 131.0 |
| 1991P | 251,767,000 | 1,134,719 | $3,007 | $2,281 | 136.1 |

NOTES: * Includes Tribal Services and Navajo-Hopi Settlement Program.
** Includes Road Maintenance program.
*** Excludes national defense and net interest payments on national debt.
N/A Not available
E Estimates
P Proposed amounts and projections

SOURCES: See text.

**Appendix Table 2. Budget Data for Selected Elements of the Federal Budget, in Constant 1982 Dollars, FY1975-1991**

[Dollar amounts in thousands, except per-capita figures]

| Fiscal Year | Bureau of Indian Affairs (Approps.) | Indian Health Service (Approps.) | Indian Education in Dept. of Educ. (Approps.) | Indian Housing in HUD (B.A. Use) | Admin. for Native Americans (Approps.) | Overall Indian Budget |
|---|---|---|---|---|---|---|
| 1975 | $1,244,917 | $494,272 | $70,884 | N/A | $53,963 | $1,864,035 |
| 1976 | $1,280,658 | $537,125 | $90,420 | $810,143 | $64,976 | $2,783,322 |
| 1977 | $1,169,924 | $756,397 | $85,010 | N/A | $49,034 | $2,060,366 |
| 1978 | $1,243,407 | $710,896 | $82,731 | $965,235 | $45,706 | $3,047,976 |
| 1979 | $1,311,953 | $724,113 | $91,266 | $1,112,341 | $42,112 | $3,281,785 |
| 1980 | $1,160,125 | $724,470 | $88,565 | $989,382 | $39,440 | $3,001,981 |
| 1981 | $1,168,561 | $925,279 | $86,[illegible]4 | $501,596 | $35,957 | $2,718,286 |
| 1982 | $970,360 | $676,157 | $77,652 | $494,300 | $28,000 | $2,246,669 |
| 1983 | $1,106,739 | $724,654 | $66,588 | $327,815 | $26,949 | $2,252,746 |
| 1984 | $889,130 | $772,894 | $63,863 | $341,783 | $26,927 | $2,094,596 |
| 1985 | $919,216 | $777,460 | $60,779 | $261,677 | $26,150 | $2,045,282 |
| 1986 | $874,950 | $762,018 | $56,403 | $263,181 | $24,378 | $1,980,931 |
| 1987 | $882,669 | $801,320 | $54,545 | $208,688 | $24,693 | $1,971,915 |
| 1988 | $883,270 | $831,672 | $52,955 | $204,287 | $24,467 | $1,996,650 |
| 1989 | $889,126 | $856,685 | $56,653 | $81,314 | $23,733 | $1,907,511 |
| 1990E | $1,035,113 | $956,662 | $56,210 | $103,914 | $24,212 | $2,176,111 |
| 1991P | $870,935 | $951,698 | $55,674 | $0 | $23,303 | $1,901,610 |

| Fiscal Year | BIA Education Program (Approps.) | BIA Indian Services Program* (Approps.) | BIA Economic Devt. Program** (Approps.) | BIA Natural Resources Program (Approps.) | U.S. Dept. of Education (Outlays) | U.S. Dept. of HHS (Outlays) |
|---|---|---|---|---|---|---|
| 1975 | $381,948 | $166,447 | $74,575 | $52,845 | $12,743,676 | $67,448,567 |
| 1976 | $386,038 | $218,092 | $83,108 | $57,071 | $12,755,943 | $74,221,870 |
| 1977 | $351,709 | $236,431 | $109,905 | $67,661 | $13,205,052 | $79,441,308 |
| 1978 | $357,622 | $261,892 | $105,848 | $106,602 | $13,901,662 | $82,173,130 |
| 1979 | $333,641 | $261,066 | $105,804 | $95,850 | $15,805,344 | $82,745,547 |
| 1980 | $315,091 | $234,688 | $90,981 | $86,624 | $17,234,539 | $89,117,853 |
| 1981 | $287,429 | $241,754 | $78,048 | $91,182 | $18,141,489 | $95,504,255 |
| 1982 | $265,606 | $235,315 | $52,884 | $84,743 | $14,808,000 | $98,020,000 |
| 1983 | $286,952 | $267,435 | $57,576 | $114,765 | $14,011,550 | $121,213,667 |
| 1984 | $237,469 | $214,814 | $54,790 | $92,532 | $14,402,043 | $112,425,255 |
| 1985 | $243,142 | $197,539 | $64,023 | $111,904 | $15,042,381 | $119,119,928 |
| 1986 | $226,098 | $185,930 | $53,436 | $118,786 | $15,529,877 | $125,881,371 |
| 1987 | $236,612 | $215,299 | $32,389 | $123,022 | $14,310,051 | $126,825,383 |
| 1988 | $196,566 | $261,499 | $32,599 | $120,371 | $15,042,045 | $131,138,500 |
| 1989 | $212,591 | $232,106 | $35,866 | $143,861 | $17,108,472 | $136,422,011 |
| 1990E | $216,446 | $226,072 | $27,865 | $94,687 | $17,038,613 | $145,964,324 |
| 1991P | $230,223 | $222,814 | $30,095 | $88,059 | $17,424,175 | $149,970,917 |

See notes at end of table.

**Appendix Table 2. Budget Data for Selected Elements of the Federal Budget, in Constant 1982 Dollars, FY1975-1991 -- Continued**

[Dollar amounts in thousands, except per-capita figures]

| Fiscal Year | U.S. Dept. of HUD (Outlays) | U.S. Dept. of Interior (Outlays) | Education Function (Outlays) | Health Function (Outlays) | Economic Development Function (Outlays) |
|---|---|---|---|---|---|
| 1975 | $12,667,791 | $3,748,735 | $27,018,550 | $21,804,384 | $7,288,364 |
| 1976 | $11,134,707 | $3,858,954 | $29,968,304 | $24,935,024 | $8,624,406 |
| 1977 | $8,630,015 | $4,778,603 | $31,358,098 | $25,708,767 | $10,432,392 |
| 1978 | $10,595,568 | $5,371,191 | $36,994,460 | $25,656,510 | $16,400,277 |
| 1979 | $11,730,280 | $5,310,433 | $38,451,654 | $26,073,791 | $13,333,333 |
| 1980 | $14,859,977 | $5,224,037 | $37,156,359 | $27,035,006 | $13,129,522 |
| 1981 | $15,829,787 | $4,745,745 | $35,860,638 | $28,580,851 | $11,242,553 |
| 1982 | $15,232,000 | $3,948,000 | $27,029,000 | $27,445,000 | $8,347,000 |
| 1983 | $15,220,404 | $4,381,136 | $25,607,315 | $27,565,929 | $7,276,227 |
| 1984 | $15,471,681 | $4,593,315 | $25,607,242 | $28,242,340 | $7,124,420 |
| 1985 | $25,897,205 | $4,350,766 | $26,458,070 | $30,245,266 | $6,925,158 |
| 1986 | $12,424,429 | $4,208,260 | $26,876,098 | $31,578,207 | $6,355,888 |
| 1987 | $13,189,097 | $4,301,533 | $25,318,569 | $34,044,293 | $4,302,385 |
| 1988 | $15,612,531 | $4,243,199 | $26,329,761 | $36,677,659 | $4,364,386 |
| 1989 | $15,581,948 | $4,127,474 | $29,045,131 | $38,313,539 | $4,244,656 |
| 1990E | $17,409,682 | $4,452,823 | $28,747,888 | $44,145,706 | $6,700,613 |
| 1991P | $16,918,594 | $4,187,210 | $30,132,777 | $46,808,868 | $5,750,250 |

| Fiscal Year | Natural Resources Function (Outlays) | U.S. Forest Service (Approps.) | U.S. Fish & Wildlife Service (Approps.) | Bureau of Land Management (Approps.) |
|---|---|---|---|---|
| 1975 | $12,387,858 | $1,741,361 | $217,024 | $672,668 |
| 1976 | $12,969,889 | $1,651,206 | $248,789 | $674,596 |
| 1977 | $14,906,389 | $2,052,052 | $320,523 | $709,529 |
| 1978 | $15,211,911 | $2,415,287 | $397,548 | $1,078,647 |
| 1979 | $15,438,931 | $2,395,674 | $434,765 | $1,076,246 |
| 1980 | $16,170,362 | $2,391,834 | $349,414 | $1,081,354 |
| 1981 | $14,434,043 | $2,247,536 | $319,252 | $1,098,874 |
| 1982 | $12,998,000 | $1,992,050 | $329,516 | $1,232,512 |
| 1983 | $12,196,343 | $2,051,492 | $317,269 | $1,067,625 |
| 1984 | $11,692,665 | $2,011,073 | $349,603 | $606,547 |
| 1985 | $12,044,184 | $2,045,521 | $391,186 | $761,682 |
| 1986 | $11,985,062 | $2,173,733 | $322,971 | $495,742 |
| 1987 | $11,382,453 | $2,014,497 | $362,893 | $589,573 |
| 1988 | $12,041,220 | $2,104,783 | $351,241 | $638,833 |
| 1989 | $12,812,352 | $2,201,269 | $361,596 | $690,112 |
| 1990E | $13,360,759 | $2,125,732 | $407,340 | $966,986 |
| 1991P | $13,350,867 | $2,016,842 | $393,634 | $740,612 |

See notes at end of table.

**Appendix Table 2. Budget Data for Selected Elements of the Federal Budget, in Constant 1982 Dollars, FY1975-1991 -- Continued**

**[Dollar amounts in thousands, except per-capita figures]**

| Fiscal Year | Total Federal Non-Defense Budget*** (Outlays) | Overall U.S. Per Capita Expenditure | Indian Per Capita Expenditure |
|---|---|---|---|
| 1975 | $375,344,013 | $1,738 | $3,173 |
| 1976 | $404,827,258 | $1,857 | $4,553 |
| 1977 | $419,132,244 | $1,903 | $3,243 |
| 1978 | $441,541,551 | $1,984 | $4,195 |
| 1979 | $438,304,071 | $1,948 | $4,152 |
| 1980 | $471,893,816 | $2,072 | $3,623 |
| 1981 | $480,810,638 | $2,089 | $3,201 |
| 1982 | $475,402,000 | $2,045 | $2,580 |
| 1983 | $489,557,267 | $2,085 | $2,496 |
| 1984 | $476,610,956 | $2,011 | $2,235 |
| 1985 | $508,690,712 | $2,126 | $2,126 |
| 1986 | $510,469,244 | $2,113 | $2,007 |
| 1987 | $496,815,162 | $2,038 | $1,947 |
| 1988 | $512,724,650 | $2,090 | $1,920 |
| 1989 | $530,441,013 | $2,143 | $1,772 |
| 1990E | $553,780,127 | $2,218 | $1,968 |
| 1991P | $556,360,342 | $2,210 | $1,676 |

NOTES:
* Includes Tribal Services and Navajo-Hopi Settlement Program.
** Includes Road Maintenance program.
*** Excludes national defense and net interest payments on national debt.
N/A Not available
E Estimates
P Projections

SOURCES: See text.

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## STATEMENTS OF SENATOR SPARK MATSUNAGA

Mr. Chairman, first of all, I would like to thank you for scheduling these timely hearings on programs of particular interest to Hawaii and the Pacific Basin. Today, I will confine my brief testimony to three programs designed to assist Native Hawaiians.

As a cosponsor, together with you, for some ten years of legislation to improve the educational status of Native Hawaiians, I was particularly pleased when the Native Hawaiian Education Act was included in the Elementary and Secondary

Education Act Amendments of 1988 and passed by Congress. For many years now, Hawaiians have listed better education for their children as one of their top priorities, and I believe that the Native Hawaiian Education Act, with programs starting at the pre-school level and including special assistance for gifted and talented students, will indeed enable Native Hawaiian children to enter the ranks of educational achievers. Moreover, although Hawaiians constitute a small minority of our population with unique and special needs, I believe that programs developed under this Act could inspire research on the special educational needs of other disadvantaged minorities. The various projects funded under the Native Hawaiians Education Act have just gotten underway, and I support an increase in funding which would permit not only their continuation but also allow for their expansion.

Secondly, Mr. Chairman, I support funding for newly-enacted legislation which would improve the health status of Native Hawaiians. One of the most attractive features of this legislation, which passed during the first session of the 101st Congress, is that it would for the most part, be administered by Native Hawaiian organizations and would permit Native Hawaiians themselves to address some of the preventable diseases such as cancer, hypertension, and diabetes which have caused Native Hawaiians to have the shortest life span of any group in our state's population.

Finally, Mr. Chairman, I am happy to report on the status of a relatively new project for Native Hawaiians. Funded under Title VI of the Older Americans Act, this new program will provide services for elderly Hawaiians at five sites on five Hawaiian islands. The sites and site directors have been selected and, beginning this spring, congregate meals will be served at all five sites. These meals will be based on a diet using traditional Hawaiian foods and should be very attractive to older Hawaiians. Initial funding of $1.4 million was provided for this program under the FY-89 Supplemental Appropriations bill. Additional funding in the FY-91 appropriations bill would permit each of the Native Hawaiian senior centers to provide some transportation for participants in the meals programs and culturally relevant recreational activities. Walk-in health screening also will be provided for program participants at the headquarters site at the Lunalilo Home on Oahu and, it is hoped, at the other four sites. In future years, a wider range of services, including meals-on-wheels will be provided to meet the needs of elderly Hawaiians living in isolated rural areas, and a second meals site will be opened on the Island of Oahu. The project was developed by a consortium of Native Hawaiian organizations assisted by the Director of the Hawaii State Office on Aging, and the grant application was submitted to the U. S. Administration on Aging by Alu Like, Inc., a non-profit, private corporation. The sponsors of the program tell me that there is already a waiting list of elderly Hawaiians waiting to participate in the program. If funding for Title VI of the Older Americans Act is increased in FY-91, a portion of the increase will be allocated to this worthy, new program for Native Hawaiians. Therefore, Mr. Chairman, I urge that the Subcommittee approve an increase in funding for Title VI.

Again, Mr. Chairman, thank you very much for this opportunity to testify in behalf of federal programs of special interest to Native Hawaiians.

###

Thank you very much, Mr. Chairman. As Chairman of the Senate Labor and Human Resources Subcommittee on Aging, which has legislative jurisdiction over the Older Americans Act, I greatly appreciate having this opportunity to testify in support of Fiscal Year 1991 appropriations for the Act.

The Older Americans Act was enacted in the mid-1960's along with the expansion of the Social Security and Food Stamp programs, and the new Medicare and Medicaid Acts as part of a government-wide effort to address the needs of senior citizens in the United States, particularly low-income and middle-income senior citizens. One of the distinctive features of the Older Americans Act was that it sought to address not just the physical and income needs of older Americans, but was also intended to assure a dignified old age for all Americans. For example, Congress found in 1965 that many elderly Americans lived isolated and lonely lives and sought to remedy this through a congregate meals program and by providing better transportation services for senior citizens. Through its nutrition programs -- congregate meals and meals-on-wheels -- the Older Americans Act has also enabled elderly Americans to lead healthier and more vigorous lives.

The Older Americans Act has been amended several times since 1965, most recently in 1987 and, today, it is without doubt one of the federal government's most successful and popular programs, enjoying a very high level of public support. I am, therefore, deeply concerned that the Administration's FY-91 budget proposes to reduce or freeze funding for these programs. I call to your attention the report on the unmet needs of the elderly, which was required by the 1987 amendments to the Older Americans Act and which shows that despite the gains made in the last 25 years, there remains an unfulfilled need for services to the elderly -- especially the poor elderly.

Moreover, with the aging of the baby boomers and with the number of elderly Americans expected to increase by at least one-third by the early to mid-21st Century, this is certainly no time to reduce funding for services provided under the Older Americans Act.

Yet, the Administration would effectively reduce services to the elderly if its Fiscal Year 1991 budget is adopted without change. For example, services under Title III of the Older Americans Act, which includes among other things nutrition services, transportation, and grants for in-home services for the frail elderly, were frozen at $710 million -- the same amount provided in FY-90. No allowance was made for needed expansion of these services, or for inflation. Services under Title VI of the Older Americans Act, which provides a variety of services to Native American elderly who are among the neediest in the nation, were also frozen at the FY-90 level, and the Administration proposes to cut funding for Title V of the Older Americans Act, also known as the Senior Community Service Employment Program (SCSEP). SCSEP, which is administered by the U. S. Department of Labor, provides job training for low-income senior citizens who work on local community service projects. Paid the minimum wage, participants in the program are usually able to move on to unsubsidized jobs in the private sector. Since Congress increased the minimum wage last year, an increase in funding for this program would be needed in any event, just to maintain the current number of participants. However, the Administration proposes to reduce funding for SCSEP by $14.2 million, a reduction which will mean the loss of more than 6,000 SCSEP jobs.

Mr. Chairman, it is clear that the Administration's budget proposals would impact most heavily on the neediest of our senior citizens. I am, therefore, requesting that this Subcommittee restore the cuts in Title V of the Older Americans Act and provide

**an increase in funding to compensate for the increase in the minimum wage. I further request that full funding of $22 million be provided for Title VI of the Older Americans Act -- an amount which will make it possible to meet the nutrition and transportation needs of American Indians, Alaskan Natives, and Native Hawaiians who often live in rural poverty and isolation. Finally, I request at least a modest increase of 4 to 5 percent be provided for Title III of the Older Americans Act so that the majority of OAA services can keep pace with inflation.**

**I ask for the Subcommittee's full and favorable consideration of this request. On behalf of our Nation's older Americans, thank you very much.**

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## STATEMENT OF THE INDIAN AND NATIVE AMERICAN EMPLOYMENT AND TRAINING COALITION

The Indian and Native American programs authorized under the Job Training Partnership Act are the major source of support for the employment and training services available to Indian, Native Alaskan and Native Hawaiian people.

In Program Year 1988, the latest period for which figures are available, the Indian program in Section 401 of Title IV of JTPA served nearly 31,000 people. Despite the very high levels of unemployment affecting nearly all Native American communities, 52% of those terminating from the program found jobs. Over 86% of those terminating from the program either found jobs or successfully upgraded their education and work skills.

Indian reservation youth, as well as Native Alaskan and Native Hawaiian youth, also receive services through a special Indian set-aside currently authorized in Title II-B of JTPA. This program serves an estimated 12,000 economically disadvantaged Native American youth.

In considering the budget request for these two Native American JTPA programs in FY 91, please keep in mind:

1. **The increase in the federal minimum wage will have a substantial impact on the number of program slots.**

Unemployment continues to be a major scourge among Indian people. Nearly two-thirds of those served by the Indian Title IV program have either been out of work for extensive periods of time or have dropped out of the labor force altogether because of a lack of jobs. As a result, most Indian JTPA grantees offer some form of work experience services as a way of building job skills and work histories, and of alleviating the burden of unemployment in Native American communities.

All of these work experience positions, including all the Summer Youth positions, are covered by the recent increase in the federal minimum wage or by even higher increases in state minimums.

A substantial increase in both the Indian Title IV and Summer Youth programs is necessary to maintain the same number of program slots.

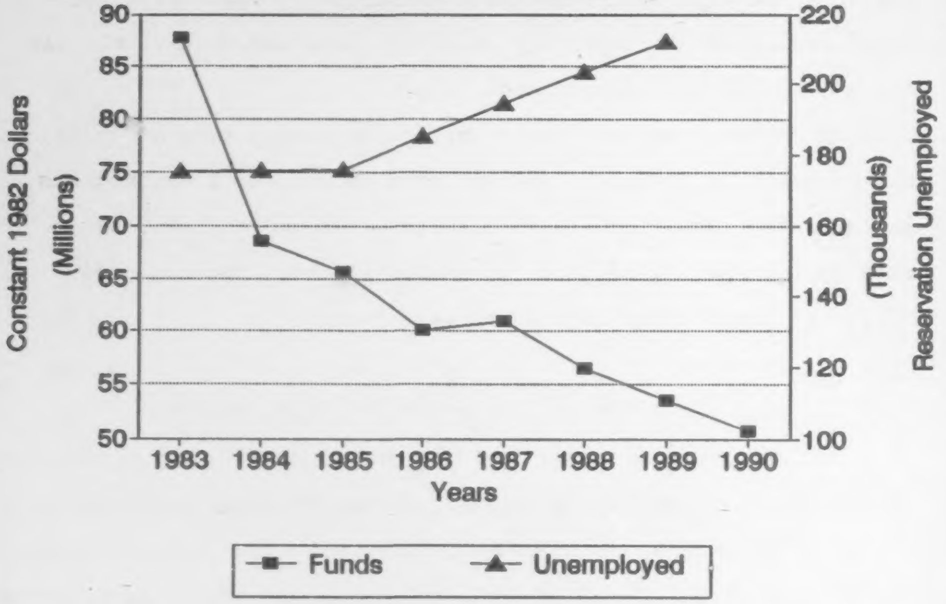
2. **Funds have shrunk over the years, but the need continues to increase.**

The attached chart illustrates the problem. Measured in constant (inflation-adjusted) dollars, the total amount of funds appropriated for Indian job training has shrunk 42% between FY 1983 and FY 1990. At the same time, figures from the Bureau of Indian Affairs' biennial labor force survey show that the number of jobless Indian workers in BIA service areas (primarily reservation areas) has gone up 21% between 1983 and 1989.

3. **The Administration has requested an increase in Indian JTPA funding for FY 91, but incorrectly calculated the amount of the increase.**

The budget request for FY 91 assumes passage of the Administration's proposed amendments to JTPA. That proposal sets the funding formula for Indian Title IV programs as 2.95% of the amount available for both youth and adult programs in

## Funding and Need for Indian JTPA Programs



Sources: Department of Labor
Bureau of Indian Affairs,
Department of the Interior

Title II. (The bill approved in the Senate Labor Committee, S. 543, would increase the percentage to 3.1%.)

This means that the Administration's request for "Federally Administered Native American Programs" should have been $79.2 million -- more than $1.6 million above the $77.6 million actually requested.

4. **Funds should continue to be appropriated for both the Native American program currently authorized in Title IV of JTPA and for services to Native American youth now funded under Title II-B.**

The Administration's request combines both of the current Indian JTPA programs into one. Indian and Native American groups oppose this approach, favoring a continued distinction between the Native American programs separately authorized in Title IV and Title II-B. The Senate Labor Committee's bill to amend JTPA, S. 543, would continue funding for both programs. Following the Administration's approach and abolishing the services now provided to Native American youth under Title II-B would radically and adversely impact reservation, Native Alaskan and Native Hawaiian communities.

In summary, we urge the Committee to appropriate at least **$80 million for Federally Administered Native American Programs as currently authorized in Title IV** of JTPA and at least **$20 million for special services to Indian youth** of the type now available under Title II-B of current law.

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## STATEMENT OF SENATOR JOHN McCAIN

MR. CHAIRMAN, I APPRECIATE THE INVITATION TO COME BEFORE YOU THIS MORNING TO EXPRESS MY DISMAY AND INDIGNATION ABOUT THE LACK OF ADEQUATE FUNDING TO ASSIST OUR NATION'S MOST NEEDY CITIZENS, NATIVE AMERICANS. IN COMING BEFORE YOU THIS MORNING, I AM SPEAKING NOT ONLY ON MY BEHALF, BUT ON BEHALF OF MY GOOD FRIEND, THE CHAIRMAN OF THE SELECT COMMITTEE ON INDIAN AFFAIRS, SENATOR INOUYE, AS WELL AS ALL OF THE OTHER MEMBERS OF THE SELECT COMMITTEE ON INDIAN AFFAIRS.

UNDER THE LEADERSHIP OF SENATOR INOUYE, THE SELECT COMMITTEE ON INDIAN AFFAIRS HAS BEEN ENGAGED IN A CAREFUL ANALYSIS OF THE HISTORIC TRENDS IN FEDERAL FUNDING FOR INDIAN PROGRAMS AND SERVICES. I WOULD ASK THAT A COPY OF THIS STUDY BE INCLUDED IN THE RECORD FOLLOWING MY REMARKS. THIS STUDY REVEALS A VERY DISTURBING FACT: FUNDS FOR INDIAN PROGRAMS AND SERVICES ARE DECLINING BY ANY ACCEPTED MEASURE.

OVER THE PAST TWENTY YEARS, THE ELIGIBLE INDIAN SERVICE POPULATION HAS NEARLY DOUBLED. YET, THE ANNUAL FUNDING FOR INDIAN PROGRAMS AND SERVICES HAS FAILED TO KEEP PACE WITH INFLATION. FOR EXAMPLE, WHILE IT IS LIKELY THAT CONGRESS WILL APPROPRIATE IN

EXCESS OF $3 BILLION FOR INDIAN PROGRAMS IN FISCAL YEAR 1991, THIS AMOUNT WOULD ONLY REPRESENT $1.6 BILLION IN CONSTANT 1982 DOLLARS. THIS CRISIS TAKES ON A NEW DIMENSION WHEN ONE FACTORS IN THE DRAMATIC INCREASE IN THE NATIVE AMERICAN POPULATION.

LET US CONSIDER FOR A MOMENT THE NEED. INDIAN AND NATIVE PEOPLES SUFFER THE HIGHEST POVERTY AND UNEMPLOYMENT RATES IN THE NATION.

IN THE AREA OF HEALTH, INDIAN AND NATIVE PEOPLES SUFFER A HIGHER RATE OF DISEASE AND ALCOHOLISM THAN ANY OTHER SEGMENT OF OUR POPULATION. THE RATE OF DIABETES AND DIABETES ASSOCIATED COMPLICATIONS IS AT LEAST 5 TIMES HIGHER FOR NATIVE AMERICANS THAN THE REST OF THE POPULATION. IN SOME AREAS OF INDIAN COUNTRY, FETAL ALCOHOL SYNDROME AFFECTS 8 OUT OF EVERY 10 BABIES. THE RATE OF SUICIDE AMONG INDIAN YOUTH FAR EXCEEDS THE NATIONAL AVERAGE. IT WILL TAKE NEARLY THIRTEEN YEARS AT CURRENT FUNDING LEVELS TO MEET THE BACKLOG OF NECESSARY CONSTRUCTION OF HEALTH FACILITIES IN INDIAN COUNTRY. THAT'S A BACKLOG OF NEARLY $500 MILLION.

LET ME NOW TURN TO THREE SPECIFIC REQUESTS WITHIN THIS COMMITTEE'S JURISDICTION.

IN THE AREA OF EDUCATION, MOST AMERICAN INDIANS AND ALASKA NATIVES DO NOT ATTEND SCHOOLS FUNDED BY THE BUREAU OF INDIAN AFFAIRS. EIGHTY-TWO PERCENT OF INDIAN CHILDREN ATTEND PUBLIC SCHOOLS. IT IS THOSE SCHOOLS WHICH ARE AFFECTED BY THE BUDGET UNDER YOUR CONSIDERATION.

I STRONGLY URGE THIS COMMITTEE TO INCREASE THE BUDGET FOR IMPACT AID FUNDS FOR STUDENTS WHO LIVE AND WORK ON FEDERAL OR INDIAN LANDS FROM THE $578 MILLION TO $658.5 MILLION FOR FISCAL YEAR 1991. EVEN THOUGH INDIAN STUDENTS MAKE UP ONLY 5 PERCENT OF THE BENEFICIARIES, SCHOOLS WITH SUBSTANTIAL INDIAN ENROLLMENTS

DEPEND HEAVILY UPON THESE FUNDS FOR THE OPERATION OF THEIR SCHOOL PROGRAMS. I WILL SOON BE URGING THE INTERIOR SUBCOMMITTEE TO INCREASE THE LEVEL OF FUNDING FOR THE OFFICE OF INDIAN EDUCATION WITHIN THE DEPARTMENT OF EDUCATION TO $119.5 MILLION TO PROVIDE GRANTS TO INDIAN CONTROLLED SCHOOLS AND SPECIAL PROGRAMS FOR INDIAN STUDENTS.

I URGE THE COMMITTEE TO INCREASE THE LEVEL OF SPENDING FOR THE ADMINISTRATION FOR NATIVE AMERICANS FROM $31.7 MILLION TO $45 MILLION IN FISCAL YEAR 1991. OF THIS INCREASE, $5 MILLION WOULD BE ADDED IN ANTICIPATION OF ENACTMENT OF S. 2075, THE INDIAN ENVIRONMENTAL REGULATORY ENHANCEMENT ACT. THIS BILL WOULD AUTHORIZE GRANTS FOR TRIBES TO IMPROVE THEIR ABILITY TO REGULATE AND PROTECT ENVIRONMENTAL QUALITY ON RESERVATIONS. THE OTHER $8.3 MILLION WOULD HELP MEET RISING COSTS AND ALLOW ADDITIONAL APPLICATIONS TO BE APPROVED. ACCORDING TO TESTIMONY BEFORE OUR COMMITTEE, TWO-THIRDS OF THE APPLICATIONS RECEIVED IN 1989 WERE REJECTED EVEN THOUGH MANY WERE MERITORIOUS AND SHOULD HAVE BEEN FUNDED.

MY THIRD, AND FINAL, SPECIFIC REQUEST OF THIS COMMITTEE IS THAT YOU SUPPORT THE $79.2 MILLION AUTHORIZED IN THE FUNDING FORMULA FOR NATIVE AMERICANS UNDER THE JOINT TRAINING AND PARTNERSHIP ACT, AND THAT YOU ADD $15 MILLION FOR THE JTPA SUMMER YOUTH PROGRAM.

UNDER THE BUDGET BEFORE YOU, THERE WOULD BE NO FUNDING FOR THE SUMMER YOUTH PROGRAM, WHICH HAS, IN THE PAST BEEN FUNDED AS A FRACTION OF THE GENERAL AUTHORIZATION. THIS HAS BEEN A PROGRAM OF GREAT IMPORTANCE FOR THE MORE THAN 12,000 INDIANS, ALASKA NATIVES, AND NATIVE HAWAIIANS WHO HAVE BEEN PARTICIPANTS IN EACH OF THE RECENT YEARS. THIS PROGRAM MUST BE PRESERVED, AND ITS FUNDING SHOULD BE ADDED TO THE $79.2 MILLION PROPOSED.

IF AMERICA IS TO HAVE THE SKILLS REQUIRED FOR THE MODERN ECONOMY, A VARIETY OF APPROACHES TO BASIC EDUCATION AND TRAINING IS REQUIRED. IT IS WIDELY KNOWN THAT THE JTPA PROGRAMS ARE HIGHLY EFFECTIVE, AND I HOPE THAT THE COMMITTEE WILL APPROVE THE INCREASE I HAVE PROPOSED.

MR. CHAIRMAN, WHILE THE PAST FIFTEEN YEARS HAS SEEN AN INCREASE IN THE PER CAPITA FUNDING FOR COMPARABLE NON-INDIAN PROGRAMS, THE SAME HAS NOT BEEN TRUE OF INDIAN PROGRAMS. IN FACT, THE STEADY DECLINE IN FUNDING IS SUCH THAT WE ARE NOW SPENDING MORE PER CAPITA ON NON-INDIANS THAN WE ARE ON OUR MOST NEEDY CITIZENS. WE ARE TALKING FEDERAL ASSISTANCE FOR THE BASIC ESSENTIALS OF FOOD, HEALTH, HOUSING AND EDUCATION.

THE FISCAL YEAR 1991 BUDGET REQUEST THAT IS BEFORE CONGRESS, AND THIS COMMITTEE, WILL ONLY SERVE TO CONTINUE THIS TREND. THE BUREAU OF INDIAN AFFAIRS IS SEEKING A NET INCREASE OVER 1990 OF LESS THAN 1%. HOWEVER, WITH PROJECTED PAY ABSORPTIONS TAKEN INTO ACCOUNT, THE BIA BUDGET WILL ONLY FURTHER DECLINE. WHILE THE IHS IS REQUESTING AN INCREASE OF 7%, AFTER PAY ABSORPTIONS AND UNREALISTIC EXPECTATIONS FOR THIRD-PARTY COLLECTIONS ARE TAKEN INTO ACCOUNT, WE ARE LOOKING AT AN INCREASE OF ONLY 2%. FUNDING FOR THE OFFICE OF INDIAN EDUCATION AND THE ADMINISTRATION FOR NATIVE AMERICANS WILL NOT KEEP PACE WITH INFLATION AND HUD PROPOSES A COMPLETE ELIMINATION OF THE INDIAN HOUSING PROGRAM, DESPITE A DOCUMENTED NEED FOR 90,000 NEW HOMES IN INDIAN COUNTRY.

IF WE ACCEPT THE ADMINISTRATION'S FISCAL YEAR 1991 BUDGET REQUEST, IT WILL ONCE AGAIN REPRESENT A DECREASE IN ACTUAL DOLLARS FOR INDIAN PROGRAMS AND SERVICES AFTER INFLATION. THIS SITUATION IS INTOLERABLE. WE ARE EFFECTIVELY COMPELLING OUR NATION'S POOREST AND MOST VULNERABLE CITIZENS TO BEAR A DISPROPORTIONATE SHARE OF THE FEDERAL FISCAL BURDEN. THERE IS NO VIABLE JUSTIFICATION FOR THIS FACT. BY CONTINUING THE TREND OF THE PAST, WE ARE

CONTRIBUTING TO THE DEPLORABLE SITUATION IN WHICH NATIVE AMERICANS FIND THEMSELVES. THIS IS SIMPLY UNCONSCIONABLE. I, FOR ONE, BELIEVE THAT WE ARE LEGALLY AND MORALLY BOUND TO DO NO LESS THAN REVERSE THE TRENDS OF THE PAST.

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## STATEMENT OF THE NATIVE HAWAIIAN GIFTED AND TALENTED PROJECT

This testimony is in support of continued funding for programs authorized by the Augustus F. Hawkins-Robert T. Stafford Elementary and Secondary School Improvement Amendments of 1989. It focuses on the demonstration project for gifted and talented Native Hawaiian children.

Title IV, Section 4006 of the referenced Act provides that the Secretary of Education shall provide a grant to, or enter into a contract with, the University of Hawaii at Hilo for the establishment of a Native Hawaiian Gifted and Talented Center at the University for demonstration projects designed to address the special needs of Native Hawaiian elementary and secondary school students who are gifted and talented and to provide those support services to their families that are needed to enable such students to benefit from the project.

### Educational Needs of Native Hawaiians

A brief profile of the educational status of native Hawaiians describes the need for this special initiative by the federal government. Native Hawaiians are characterized by a generally low socio-economic profile as evidenced in their poor educational performance in school, low participation (in numbers) in higher education, overrepresentation in the state's welfare program, and lowest median income among the four main ethnic groups in Hawaii.

### Underrepresentation of Native Hawaiians in Gifted and Talented Programs in the State of Hawaii

As reported last year, of the 5,507 students in the State of Hawaii's Department of Education gifted and talented programs, Native Hawaiians constitute only 11 percent of the total, considerably below their proportion in the general population. Worse, only 9 percent of the Native Hawaiian students enrolled in a gifted and talented program at the elementary level remain in the high school program. There is an 81 percent drop in participation by Native Hawaiian children between the elementary and intermediate school levels and a 46 percent drop between the intermediate and high school levels.

It appears that the specific needs of these young people are not being met by existing programs.

### Justification for the Native Hawaiian Gifted and Talented Project to be Located at the University of Hawaii at Hilo

There are a number of factors that make the University of Hawaii at Hilo an appropriate site for having a Gifted and Talented Center for Native Hawaiian Children.

Native Hawaiians constitute the largest ethnic group of high school students on the Island of Hawaii, and more than half of all births in Hilo are to Native Hawaiians, with the result that this population will dominate the elementary schools for some years.

The natural environment of the Island of Hawaii is a living laboratory for the sciences -- geography, oceanography, aquaculture, astronomy, climatology, geology, marine biology, agriculture, and animal husbandry. The University of Hawaii at Hilo's faculty do, in fact, use the island setting to provide opportunities for hands-on research and study.

The pockets of communities throughout the Island of Hawaii that still practice Hawaiian culture and traditions facilitate further study of Hawaiian language and culture, and provide for an opportunity to compare family teaching and learning practices with school teaching and learning practices.

The small size of the University promotes a "community" approach and thus makes for greater cooperation of faculty and staff in facilitating a project like the Gifted and Talented Project. This is substantiated by the 18 university faculty and educational specialists who conducted class for over 100 gifted and talented Hawaiian children on Super Science Saturday on March 10.

This leads to the next argument for continuing the Project at the University of Hawaii at Hilo, that is, the availability of expert faculty resources. Faculty at the University of Hawaii at Hilo span nearly every major discipline area. Special programs are already developed that utilize the environment of the Island, i.e., geology - studying active volcanoes, astronomy, marine options program, aquaculture.

The University of Hawaii at Hilo has a history of commitment to serving the educational needs of Native Hawaiians. Over the past ten years, the percentage of Hawaiians representing the student population has tripled. This is a result of the development of academic, research, leadership, and student support programs for Hawaiians. In addition, the University has developed an environment that is responsive to the Hawaiian culture and traditions by integrating some of the traditional Hawaiian rituals into commencement activities and other formal events.

## Program Goals and Objectives of the Native Hawaiian Gifted and Talented Project

The purposes of this project are to (1) establish a Native Hawaiian gifted and talented center, and (2) create demonstration projects that "address the special needs of Native Hawaiian elementary and secondary school students who are gifted and talented, and provide those support services to their families that are needed to enable such students to benefit from the project."

To address the problem of underrepresentation of Native Hawaiians in gifted and talented programs, the primary goal of the Center is to provide programs and services to increase their participation in gifted and talented areas. The following objectives are set up to accomplish this goal:

1. To review, develop, and recommend policies and procedures for identifying and assessing Native Hawaiian gifted and talented children.

2. To develop access for Native Hawaiian gifted and talented children into existing gifted and talented programs.

3. To plan, develop, and implement experimental and innovative demonstration projects for Native Hawaiian gifted and talented children.

4. To provide support services to families of identified Native Hawaiian gifted and talented children.

5. To incorporate Native Hawaiian values, culture, language, and history into the gifted and talented curriculum and activities.

6. To provide in-service training for school personnel for (a) encouraging their active involvement in the early identification of potential candidates, (b) sensitizing them to the emotional, psychosocial and educational needs of Native Hawaiian gifted and talented children, (c) using the identification and assessment model developed by the Center, and (d) incorporating successful and appropriate program activities into the schools.

## Program Impact and Accomplishments

### 1. Identification and Assessment

The Center has developed several activities which attend to the issue of identification and assessment of gifted and talented Native Hawaiian Children.

a. Developing identification and assessment procedures for specific program areas
The Super Sessions being conducted in Spring of 1990 utilize assessment measures specific to a particular talent. Students submit an application that includes recommendations from teachers and professionals who can attest to the level of proficiency of the applicant. The student presents a sample of his or her proficiency, capability, and interest in a form appropriate to the talent or gifted area. This format addresses several hypotheses of why Hawaiians are underrepresented. It allows for the person who can best attest to the student's capability in the talent area to submit a recommendation. Sometimes the classroom teacher does not have the opportunity to observe the candidate's ability in the areas of the Arts or Leadership. Also, many Hawaiian children have not had the opportunity to demonstrate their capability in a particular talent area. Thus, if a student can demonstrate a high interest level, he/she will be considered for the program area. Barbara Clark, a nationally known expert in the field of gifted education states, "the identification of such individuals must include the opportunity to have experiences in all of these areas, and in settings appropriate to the individuals' cultural heritage."

b. Developing procedures and measures for identifying gifted and talented students who may not be identified using traditional measures
The Center is working with two high schools in Hilo to identify "bright students who are falling between the cracks." The procedure is a lengthy one in which school officials, teachers, parents, and students work

together in identifying the characteristics that this target group exhibit. All teachers and students participate in the actual process of identification, utilizing nomination sheets developed by the group of administrators, teachers, parents, and students. This is consistent with some of the research and teachings of Mary Frasier, consultant to the Center. She espouses the utilization of procedures that are best able to measure capability appropriate to how students manifest their giftedness. It is hoped that if successful, other schools statewide and nationally can utilize this model.

c. Providing teachers with opportunities to better identify gifted and talented Native Hawaiian students.
To date, the Center has provided teachers the opportunity to participate in three workshops conducted by nationally-known experts. The first was by Dr. Joyce VanTassel-Baska from the College of William and Mary; the second, by Dr. Robert Sawyer from Duke University, and third, by Dr. Mary Frasier from University of Georgia.

The Center plans to provide more opportunities and more research oriented work through course related workshops.

2. Developing Access to Existing Gifted and Talented Programs

There are a number of gifted and talented programs that exist in the state. With limited resources, the Center has explored how more Hawaiian students can participate in these existing programs. By providing these programs with information about the Center's identification procedures and program content, the Center has enhanced the chances of more Hawaiians participating in these programs.

3. Demonstration Programs

Programs are developed based on the needs of the students and the availability of resources. The Programs that provide direct services to students are either on Saturdays, spring break, after school, or during the summer. The one exception is the High School Demonstration Project which is conducted in partnership with the State of Hawaii Department of Education. These are enrichment programs and utilize the faculty resources of the University to work with the gifted and talented students. Based on the activities conducted as part of the Super Series, it appears that the Center is right on target in identifying gifted students, and in filling a void by providing enrichment educational activities. Many students and parents have voiced their pleasure in having these gifted activities and the need to provide more.

The following is a calendar of events for Spring 1990:

| Date | Activity | Number of Participants |
|---|---|---|
| 01/05/90 | Teacher Education Workshop<br>Minority Gifted Students<br>Dr. Joyce VanTassel-Baska | 60 teachers |
| 01/11/90 | Teacher Inservice<br>Prof. Pualani Debus<br>Creative Dramatics | 50 teachers |
| 01/31/90 | Teacher Inservice<br>Identifying gifted students | 120 teachers |
| 02/03/90 | Super Psychomotor Saturday<br>Makahiki Event | 180 children |
| | Parents' Information/Workshop | 100 parents |
| 02/04/90 | Audition & Selection<br>Childrens' Chorus | 25 Children |
| 02/05/90 | Community Presentation "Summer Educational Enrichment Opportunities"<br>Presentors: Dr. Robert Sawyer<br>Dr. David Sing | 80 parents, students, teachers |
| 02/06/90 | National Advisory Council Meeting | |
| 02/07/90 | Community Presentation (same as 02/05/90) - Maui | 25 parents, students, teachers |
| 02/08/90 | Community Presentation (same as 02/05/90) - O'ahu | 200 parents, teachers, |
| 02/11/90 | Deadline and Final Judging of Art - Logo Contest | 100 entries |
| 02/21/90 | High School Inservice<br>Identifying Gifted Students | 100 teachers |
| 02/21/90 | Elementary School Inservice<br>Creative Dramatics and Related Arts | 30 teachers |
| 02/26/90 | Teacher Education Workshop<br>Dr. Mary Frasier | 50 teachers |
| 03/10/90 | Super Science Saturday | 100 children |
| 03/21/90 | Mentorship Program<br>Application Submission | 20 children<br>20 mentors |
| 03/27-30 | Super Hawaiian Culture & Language Spring Break | 250 children |
| 04/28/90 | Super Arts Saturday | 200 children |
| 04/30/90 | Teacher Education<br>Stuart Tonemah | 60 teachers |
| 05/01/90 | National Advisory Council Meeting | |
| Summer | Summer Educational Enrichment Programs | 100 children |

### 4. Student and Parent Support Services

The student and parent support services are an essential part of a child's participation in gifted and talented activities. The program provides both the student participants and their families with information and support as a means toward enhancing the students' success in learning.

The program integrates self development and guidance activities, and ensures continuity of academic and support services.

The parent support component includes specific ways that parents may be advocates for their children's success in school and in the program.

### 5. Integrating Havaiian Cultural Aspects into the Programs

It is important that students feel positive about themselves as Havaiians. A lack of positive role models and negative stereotyping of Native Havaiians have resulted in Native Havaiians perceiving limitations to their academic and career capabilities. The Center promotes positive Havaiian role models and shows how Havaiian culture can be a positive influence in academic enhancement.

## Continuing Issues

Current issues in gifted education include the identification and assessment of gifted and talented students. The procedures being used in the various programs through the Center are being documented for dissemination statewide and nationally to appropriate populations. The director is collaborating with Mary Frasier from Georgia and Stuart Tonemah from Oklahoma to present findings from their respective works at the National Association of Gifted Children in November 1990.

The Center is working closely with the State of Havaii Department of Education to review other issues within gifted education that impact on Native Havaiians.

Continued enrichment and other educational program opportunities for Havaiian students are being developed. The Center is developing programs that will be a continued resource to the gifted child, teacher and family as a means to develop the child as a state and national human resource for the future.

## Summary

The Center for Gifted and Talented Native Havaiian Children at the University of Havaii at Hilo addresses the need to increase the number of Native Havaiian children to benefit from gifted programs and services. The current services provided by the Center appear to be facilitating appropriate means to identify gifted Havaiian children and program activities that enhance their talent.

The need exists to have increasingly more educational enrichment opportunities for Native Havaiians. The Center at the University of Havaii at Hilo provides direct service to only a small population of Native Havaiians statewide. The Center seeks to develop more opportunities to Havaiians on other Islands.

Through continued and increased funding, the Center can continue to develop more opportunities for gifted Havaiian children.

## SUPER SCIENCE SATURDAY, March 10, 1990

The first Super Science Saturday for native Hawaiian youth, sponsored by Nā Pua No'eau, the Center for Gifted and Talented Native Hawaiian Children, was held on March 10th at the University of Hawaii at Hilo campus. Classes for students from kindergarten through grade 12 were held in the Life Sciences, Physics, Chemistry, Astronomy, and Geology buildings between the hours of 9:00 a.m. and 4:00 p.m. Intermediate and high school students also spent part of their day at Onekahakaha Beach tidepools; taking plankton tows and analyzing ocean water samples in Hilo Bay; exploring the Hawaii Volcanoes National Park; and involving themselves in the computer technology used in seismology today at the HVNP Observatory.

The majority of the 19 instructors for the day were university professors, with the remaining teachers being field scientists or professional educators. Over 125 students were serviced with the help of 32 volunteer parents, Hawaiian Leadership Development Program students, UHH Science Methods students and Na Pua No'eau staff.

Students in kindergarten through grade 2 were exposed to mathematics and physics through "Amazing Bubbles," to proper nutrition through "Food and You," and to the world of the insects through "BugPlay."

Third through fifth graders experienced such sessions as "Exploring Hawaii's Plants," Kitchen Chemistry," and "Rockin' Rocks."

Students in the sixth through eighth grades had a day-long session in which half of their day was a classroom experience in such topics as "You Are What You Eat," "Magic of Chemistry," and "Celestial Navigation." The other half of their day was spent tidepooling; collecting and analyzing ocean plankton and water; and viewing microscopic marine organisms using the Scanning Electron Microscope.

Senior high school students enjoyed morning sessions on "Sun Fun" and "Hawaiian Mushrooms and Simple Plants" followed by an afternoon field trip to the Hawaii Volcanoes National Park which included a hike featuring the geological and biological features of the area and a presentation at the Observatory entitled "Seismology Yesterday and Today."

Feedback from students, parents, and instructors has been highly positive to date, with student participants already requesting mentors in such scientific areas as chemistry and marine biology.

**SUPER SCIENCE SATURDAY**
**March 10, 1990**

| PRESENTER | TOPIC | NO. OF STUDENTS | GRADE | TIME | BUILDING, ROOM | TEAM NAME |
|---|---|---|---|---|---|---|
| Dr. Walt Dudley<br>UHH, Natural Sciences<br>Hilo, HI 96720 | "Ocean Sampling" | 21<br>21 | 6,7,8<br>6,7,8 | 9:00-11:25 a.m.<br>12:30- 3:25 p.m. | meet in PB13, Rm 2 | 'Akala Palaunu |
| John Coney<br>UHH, Natural Sciences, MOP<br>Hilo, HI 96720 | "Scanning Electron Microscope" | 21<br>21 | 6,7,8<br>6,7,8 | 9:00-11:25 a.m.<br>12:30- 3:25 p.m. | meet in PB13, Rm 2 | 'Akala Palaunu |
| Dr. William Heacox<br>UHH, Natural Sciences<br>Hilo, HI 96720 | "Sun Fun" | 14 | 9-12 | 9:00- 9:45 a.m. | LS, Rm 15 | Anuenue |
| Dr. Don Hemmes<br>UHH, Natural Sciences<br>Hilo, HI 96720 | "Hawaiian Mushrooms & Simple Plants" | 14 | 9-12 | 9:50-10:35 a.m. | LS, Rm 15 | Anuenue |
| Dr. Jim Kauahikaua<br>USGS, P.O. Box<br>HVNP, HI 96718 | Field Trip Prep | 14 | 9-12 | 10:40-11:25 a.m. | LS, Rm 15 | Anuenue |
|  | Enroute to from Hilo to HNVP (lunch on van with Geological Tour along the way) |  |  | 11:45-12:30 p.m. |  |  |
|  | Into to HVNP & Hike (conducted by Mardi Lane) |  |  | 12:30- 1:30 p.m. | meet at Visitors Center |  |
|  | Enroute from Visitors Center to Observatory |  |  | 1:30- 1:45 p.m. |  |  |
|  | "Seismology Yesterday Today" (presentation by Tom English & Carl Johnson) |  |  | 1:45- 2:45 p.m. | Observatory |  |
|  | Enroute from HVNP to Hilo |  |  | 2:45- 3:30 p.m. |  |  |
|  | Awards |  |  | 3:30- 4:00 p.m. | W, Rm 1 |  |
| Mardi Lane<br>Div. of Interpretation<br>P.O. Box 52<br>HVNP, HI 96718 | "Introduction to HVNP" & hike discussing native flora, fauna & geology | 14 | 9-12 | 12:30- 1:30 p.m. | meet at Visitors Center | Anuenue |
| Tom English<br>USGS, P.O. Box 51<br>HVNP, HI 96718 | "Seismology Yesterday & Today" (stressing computer applications) | 14 | 9-12 | 1:45- 2:45 p.m | Observatory | Anuenue |
| Dr. Carl Johnson<br>UHH, Natural Sciences<br>Hilo, HI 96720 | "Seismology Yesterday & Today" (stressing computer applications) | 14 | 9-12 | 1:45- 2:45 p.m. | Observatory | Anuenue |

Box 1063
Kamuela, HI.
March 15,1990

Dear Dr. Sing, Dr. Anderson, Dr. Kho, Dr. Hunter, and Ms. Pinner,

I certainly enjoyed the Super Science Saturday sessions. It was really neat to be at U.H. and learning new things. I really liked holding the pumice at Rockin' Rocks - it was so light! We are studying geology in school right now and you made it more interesting. I enjoyed watching the different kitchen materials turn different colors when we added purple cabbage juice. I added the leaves from "Kingdom of the Plants" to my leaf collection.

I wish that you could have more Super Science Saturdays. They are fun and there is so much to learn from them about science.

With aloha,

Love
Lindsey

## Super Athletics Saturday - February 3, 1990

The first event developed by Nā Pua No'eau to identify gifted and talented Hawaiian children was designed to combine challenges in the psychomotor area with cultural history in an event called **Super Athletics Saturday/Makahiki.** Makahiki was the seasonal celebration of the *wā kahiko,* or ancient Hawai'i, which honored the god Lono, whom the *po'e Hawai'i* (Hawaiian people) looked to for assurance of a bountiful existence. During the Makahiki months, roughly October through February, the *po'e Hawai'i* tested their mettle with various competitive games that would determine the skill of warriors and the cunning of leaders.

Nearly 200 participants from kindergarten through 12th grade assembled at the University of Hawai'i at Hilo Gymnasium and adjoining field to work with Nā Pua No'eau staff members, several community Makahiki specialists, and assistants from the UHH Hawaiian Leadership Development Program and The UHH Vulcan Women's Volleyball team. In addition to the children, 100 parents came to the Makahiki to learn about the Center's programs and discover ways to enhance their children's education. They met with staff members, attended a special session designed to strengthen parenting, and observed their children's efforts throughout the event.

The day began with a *hui* , or gathering, where children and parents where introduced to the Center's staff and the concept of Makahiki, centering on the idea of *"He Hawai'i au, mau a mau,"* or "I am a Hawaiian--forever." All participants were assigned to be in a group that was given the name of a specific Hawaiian flower. Each group was lead by a college student leader or athlete who helped the children feel more comfortable with each other by making up a cheer to urge their group on to victory in the Makahiki using Hawaiian phrases that translate into positive concepts, such as "Work together!," and "Go forward." The cheer was used throughout the day when the children worked as a team.

With the fabric and wood symbol of Lono overlooking the playing area, the elementary level children immediately began Makahiki games after the *hui.* Points were tallied while the assistants worked on identifying the children who excelled as athletes.The gymnasium came alive with groups attempting the following activities:

*pahe'e,* sliding darts
*o'o ihe,* spear throwing
*kukini,* foot race
*ulumaika,* stone bowling
*huki huki,* tug-o-war
*umauma,* arm wrestling
*haka moa,* one-on-one balancing

Older children in intermediate and high school first attended classes to learn about the history of the Makahiki and its inherent values that have significance to athletes today. Activities in the classes emphasized a hands-on approach to learning where participants did exercises that demonstrated "endurance" and "cooperation," etc. Time was spent with the Makahiki implements to allow the children to become familiar with their usage. The entire afternoon was devoted to Makahiki games that greatly tested the abilities of the older participants, as they rotated on the athletic field with footraces, group Makahiki games, and one-on-one challenges.

The participants spent their lunch time with role model student athletes and leaders. They were able to ask them about the difficulties and delights of being young, Hawaiian, and active in the athletic and academic arenas.

At the end of the sessions, all the children were given Certificates of Participation and outstanding teams were recognized for earning the most points. The cheers were again used to foster spirit and team work. Finally, the children were asked to evaluate the day and make suggestions for other Nā Pua No'eau activities.

The children characterized the Super Athletic Saturday that followed as "being like a family," and a time to "learn a lot of things about confidence, team work, and leadership." They thought that the day was special because of the "use of Hawaiian words," "the people who taught us a lot," "how to do and make things," and "a time when only people of Hawaiian blood came together." An overwhelming positive response (100%) to the statement, "The program leaders helped me learn about my abilities," attests to the growth experienced by Super Athletic Saturday participants.Best of all were their comments about what should be changed: "Should be longer," and "Have it more often!"

## CORPORATION FOR PUBLIC BROADCASTING

### STATEMENT OF THE NATIONAL PUBLIC RADIO

Mr. Chairman and members of the Subcommittee, I am pleased to testify in support of appropriations for the Corporation for Public Broadcasting (CPB). CPB is authorized at $285 million for FY 1993, and I urge the Subcommittee to appropriate the full amount. In addition, $200 million has been authorized over three years for replacement of the public broadcasting satellite interconnection systems; $133.06 million of that amount has been appropriated. National Public Radio (NPR) requests that the remainder of the authorized funds, $66.94 million, be appropriated in FY 1993.

### PUBLIC RADIO'S MISSION:MOVING IN NEW DIRECTIONS

NPR, now celebrating its 20th anniversary year, represents 384 public radio stations that provide news, information, cultural, and performance programming to 11.6 million listeners across the country. NPR's audience has increased by 1.6 million in the past year. The public radio system has embarked on an ambitious strategy to bring quality programming choices to a larger and more diverse segment of the population. Public radio's distinctive blend of news and cultural programming, now available to 86 percent of the population, moves listeners beyond today's conventions and offers them new insights about themselves, their communities, and the world.

The role that stations play in their local communities is also crucial. A recent example is found at KERA-FM in Dallas where a local businessman promised to donate $1 in food to a food bank for every $2 pledged by listeners during a fundraiser. KERA's audience responded with a record $26,705 in pledges, resulting in a donation of $13,352.50.

Public radio has established itself as a strong, vital service for the nation. Looking to the future, National Public Radio last year initiated a strategic planning process to give it direction and to shape its priorities for the 1990s. This process led to a reexamination of NPR's mission to ensure that it reflects the importance of meeting the changing needs of a society with stronger cultural, racial, and ethnic identities.

### EXPANSION OF PUBLIC RADIO TO REACH UNSERVED & UNDERSERVED AREAS

Shortly after NPR's strategic planning process began, in March of 1989, the Public Radio Expansion Task Force convened under the auspices of the Carnegie Corporation and CPB. The major findings of the Task Force are two-fold. First, it concluded that it is possible for public radio to increase its reach from 86 to 95 percent of the population by the year 2000. The Task Force states that this can be accomplished in part by increasing the number of CPB-qualified stations, by expanding the satellite interconnection system, and by establishing new downlinks at 50 existing stations currently without such facilities. Downlinks will allow these stations to receive thousands of hours of national programming for little or no cost.

The second major finding was that expansion of public radio service also requires new programming initiatives to serve individuals whose needs are not being met by the offerings of existing stations. There are 26,000 hours of national programming competing for only 40 percent of a station's air time. Because there is not enough air time on one or two stations' schedules, much of public radio's national programming goes unheard in many communities. Adding 50 interconnected public radio stations would allow more programming to be heard, including some targeted to audiences that are presently underserved.

CPB recently instituted two new grant programs to assist in expanding public radio's reach and diversity. These programs will help stations that already provide an important service to their local communities, but that could do more with a satellite downlink and additional funding through CPB grants. One station that will benefit from these programs is KKFI-FM in Kansas City, Missouri, a truly multicultural station that programs in Spanish and English and has on-air volunteers from the Caribbean, African American, Latino, and Asian communities. Others are KNNB-FM in Whiteriver, Arizona, licensed to the Apache Tribe and broadcasting in Apache and English; Latino-controlled WDNA-FM in Miami, Florida broadcasting in Spanish and English; and WVMR-FM in Dunmore, West Virginia, the sole broadcast service for a poor rural community.

## PUBLIC RADIO STRIVES TO MEET CULTURAL CHALLENGES OF THE '90S

### NPR presents diverse cultural perspectives to listeners

NPR's recently-completed Strategic Plan has helped shape NPR's goal of meeting the artistic and cultural challenges of the 1990s and harnessing the strengths of the radio medium to express the diversity of American culture.

Public radio as a whole has a special mission to fulfill. Fueled by a flexibility which allows radio to respond quickly to a dynamic society, public radio can help shed light on the cultural characteristics of our changing nation. NPR is developing programming that embraces this new philosophy, including MAKING THE MUSIC, an exploration of what makes American music truly American. Hosted by Wynton Marsalis, the series will use live performance, historical recordings, and re-creations to illustrate the roots and cross-influences of American music, and chart its growth in the 20th century.

Another innovative venture is THE CAULDRON:RACE AND CULTURE IN AMERICA, a series providing an honest and intricate examination of the interwoven, yet separate, issues of race and culture in America's growing pluralism.

AFROPOP WORLDWIDE continues to grow in popularity. This lively eclectic mix of music from Africa, partially funded by CPB's Radio Program Fund, is now carried on 115 stations nationwide. Another recent addition is BLUESSTAGE, hosted by Ruth Brown, which showcases live blues performances. Also a recipient of CPB funds, it found its audience almost immediately and is now carried by approximately 140 stations. The popular humorist and storyteller Garrison Keillor is back on the airwaves with American Public Radio's "American Radio Company of the Air"; other APR offerings include "Whadda ya Know," "Mountain Stage," and the award-winning "St. Paul Sunday Morning."

### Local stations contribute to cultural lives of their communities

Local public radio stations play a major role in the cultural lives of their communities. In addition to broadcasting local concerts and keeping the community informed of upcoming events, many stations air other regular programs that address more specialized needs.

WFPK/WFPL-FM in Louisville, Kentucky, airs "Kentucky Center Readings," featuring readings by area writers; the station is also developing the "Louisville Radio Repertory Theatre" -- radio dramas written for and by teenagers. WDUQ-FM in Pittsburgh, Pennsylvania, which has a growing Indian audience, airs an ethnic music program featuring music from India. And KSOR-FM in Ashland, Oregon, is working with local Hispanic organizations to develop a Sunday afternoon program devoted to music and news of interest to this segment of the community.

WBEZ-FM in Chicago provides extensive coverage of local music festivals, including national broadcasts of the Chicago Jazz Festival and the Chicago Blues Festival. The station also recently began airing "Artistic License," a two-hour newsmagazine covering the area's art, music, and theatre scene.

NPR's national news coverage is comprehensive & thought-provoking

National Public Radio is best known for its award-winning newsmagazines ALL THINGS CONSIDERED, MORNING EDITION, and WEEKEND EDITION. Along with NPR's hourly newscasts, American Public Radio's "Monitoradio," a daily half-hour news program from the Christian Science Monitor, and its new weekday business program "Marketplace," add to public radio's comprehensive news presence.

NPR's weekly series HORIZONS also won several awards in the past year: "And Justice for All," an independently-produced documentary that examined the plight of poor New York City tenants facing eviction without legal aid, won the top New York State Bar Media Award; "The 9 to 5 Danger Zone:Occupational Hazards," an investigation of occupational hazards faced by women, won a Women at Work Broadcast Award; and "Date Rape:The Crime of Ordinary Men" won an Ohio State Award and a Silver CPB Award.

National Public Radio has also begun work on its Specials Project, a new approach to public radio news that will use an extensive outreach program to link listeners, schools, businesses and community organizations with their public radio stations. The first special, which will air in September, 1990, examines the attitudes of youths toward prejudice and asks whether they will be prepared to cope in the increasingly diverse world of the 21st century.

Local stations' news & public affairs programs meet community needs

In addition to national programming, news on public radio includes locally-produced programming that is responsive to the special needs of stations' communities.

KCHU-FM in Valdez, Alaska, (serving only about 8,000 people) broadcast extensive, award-winning coverage of the Exxon Valdez oil spill, which was relied on by all the commercial networks until their own reporters could reach the scene. The station devoted its entire annual news budget to coverage of the spill.

In Louisville, Kentucky, WFPK/WFPL-FM airs "Louisville Forum," which covers monthly meetings where local issues are discussed. The station has a program in development called "Environmental Minute," a series of daily, 60-second modules discussing environmental issues.

Florida stations WUSF-FM and WSFP-FM together reach one-third of the state's population. The stations' award-winning news coverage last year included "Christian Science on Trial," a two-part series that explored the legal and ethical questions about freedom of religion and the responsibility of the state to protect children.

## PLANS FOR SECOND GENERATION PUBLIC RADIO SATELLITE INTERCONNECTION SYSTEM ARE WELL UNDERWAY

The importance of the public radio satellite system cannot be overstated. The current satellite has enabled public radio stations to enjoy a growing variety of program choices made available by hundreds of producers across the country. In 1988, more than 21,000 hours of programming were available; in 1989, the figure was 26,000 hours. Studies indicate that this growth will continue, requiring additional distribution capacity.

This subcommittee has already appropriated $133.06 million of the authorized $200 million for replacement of the public broadcasting satellite interconnection systems, which will go dark by mid-1991. NPR wishes to thank the committee for this past support, and to request that the remaining $66.94 million be appropriated in FY 1993.

On February 28, 1990, National Public Radio signed a contract with Hughes Communications Galaxy for C-band transponder capacity which is intended to provide public radio with continuity and flexibility for growth approximately through the year 2005 -- four years longer than the original projections -- at a cost nearly $5 million less than previously estimated.

The replacement satellite system takes into account public radio's commitment to reach unserved and underserved audiences, including the fourteen percent of Americans who are still unable to hear any public radio signal. In addition, the planned system will provide service to existing stations not now a part of the interconnection system.

Mr. Chairman, National Public Radio requests that the full $285 million authorized for CPB, plus the remaining $66.94 million for satellite replacement, be appropriated for FY 1993. The accomplishments of public radio thus far are many, yet we can do so much more. Public radio is ready, with your help, to respond to the rapid social, economic, technological, and cultural changes that will face America in the 1990s and beyond.

# LETTER FROM THE PUBLIC RADIO EXPANSION TASK FORCE

March 19, 1990

Honorable Tom Harkin, Chairman
Subcommittee on Labor, HHS and Education
Senate Appropriations Committee
U.S. Senate
Washington, DC 20510

Dear Mr. Chairman:

We are pleased to forward to you a copy of *Public Radio in the 1990s: Fulfilling the Promise.*

This report was prepared by the Public Radio Expansion Task Force, an independent working group representative of public radio's interests at both the station and the national level.

Our broad goal is to assure that public radio is available to, and used by, more of the American people. Our plan will achieve:

- Major progress toward full national coverage.
- Increased station effectiveness.
- Greater efficiency from current resources.
- New programming that will increase and diversify public radio's audience.

The report has been widely endorsed within the public radio community -- by the Corporation for Public Broadcasting, National Public Radio, the National Federation of Community Broadcasters, and several public radio regional organizations. CPB has committed substantial funds to start work on the recommendations.

The full plan outlined in the report requires further resources from both the public and private sectors. We hope you will support funding for public broadcasting at the full authorized level, so that public radio can fulfill the promise of public service that both Congress and we in public radio have envisioned.

Sincerely,

Dale K. Ouzts

Dale K. Ouzts
Chairman

# PUBLIC RADIO IN THE 1990S
# FULFILLING THE PROMISE

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## THE MEMBERS OF
## THE PUBLIC RADIO EXPANSION TASK FORCE

Lynn Chadwick
PRESIDENT, NATIONAL FEDERATION OF
COMMUNITY BROADCASTERS
*Washington, DC*

Dennis Connors
DIRECTOR, PUBLIC TELECOMMUNICATIONS
FACILITIES PROGRAM/NTIA
DEPARTMENT OF COMMERCE
*Washington, DC*

Augustine Dempsey
DIRECTOR OF BROADCAST SERVICES
CORPORATION FOR PUBLIC BROADCASTING
*Washington, DC*

Tom Livingston
VICE PRESIDENT & GENERAL MANAGER
WETA-FM
*Washington, DC*

Hugo Morales
EXECUTIVE DIRECTOR
RADIO BILINGUE
*Fresno, California*

Michael L. Morgan
DIRECTOR OF RADIO
PUBLIC RADIO IN MISSISSIPPI
*Jackson, Mississippi*

Midge Ramsey
VICE PRESIDENT, REPRESENTATION
NATIONAL PUBLIC RADIO
*Washington, DC*

Wayne C. Roth
GENERAL MANAGER
KUOW-FM
*Seattle, Washington*

Joan G. Rubel
GENERAL MANAGER
WFCR-FM
*Amherst, Massachusetts*

Doug Sweet
GENERAL MANAGER
KMUN-FM
*Astoria, Oregon*

Bruce Theriault
SENIOR VICE PRESIDENT & DIRECTOR,
NETWORK OPERATIONS
AMERICAN PUBLIC RADIO
*St. Paul, Minnesota*

Thomas J. Thomas
CONSULTANT
STATION RESOURCE GROUP
*Takoma Park, Maryland*

Dale K. Ouzts, Chairman
GENERAL MANAGER
WOSU-AM/FM/TV
*Columbus, Ohio*

# PREFACE

The entire question (and subsequent ramifications) of how public radio will expand in the 1990s is an important issue that deserves the close attention of the professionals in public radio today.

This report presents the results of thousands of hours of thought among public radio professionals on the future of public radio. The depth and breadth of the contributions by people across the nation only made the work of the Task Force members more complex. No bad ideas were offered. None of the ideas offered could be easily discarded or omitted.

Public radio has been expanding since the Public Broadcasting Act of 1967 created the term "public broadcasting" to replace the misunderstood term of "educational broadcasting." New stations appeared every year, but there was insufficient attention to systems or planned growth. A few short years after the Corporation for Public Broadcasting (CPB) was founded by Congressional mandate, it issued a plan for expansion of public radio. Naturally, the number of public radio stations increased and their varied services matured. Before long, the targets of the plan having been hit, attention shifted from expansion to system support and improvement. But public radio service was yet to be made available to many people, and services still foundered in some areas where they had been made available.

The Public Radio Expansion Task Force was convened in March of 1989, in the belief that it was again time to develop a systematic method of extending public radio services. The Task Force composition reflects the interests of both individuals and organizations, stations of various sizes, market and licensee differences, and diverse opinions on a myriad of subjects related to expansion. Six national organizations are represented on the Task Force, and seven station representatives come from across the country, together representing all sizes and types of licensees, many types of programming and target audiences, and stations that benefit from the federal support of public radio and those stations that do not.

The Task Force, all public radio stations, and organizations supporting public radio owe a debt of gratitude to the Carnegie Corporation of New York for funding many of the Task Force's expenses. The Carnegie Corporation has supported work that deals with the future of public broadcasting on several occasions, including the landmark study that provided much of the content of the Public Broadcasting Act of 1967. All the members of the Task Force join me in expressing our appreciation for the Carnegie Corporation's support.

The Corporation for Public Broadcasting also contributed to the Task Force's expenses and hosted most of our meetings.

While the Task Force was meeting from coast to coast with station representatives at national, regional, and state meetings, lots of people were working hard even if they were not always present or visible. As Chairman, I want to thank first Tom Thomas and Terry Clifford, of the Station Resource Group (SRG), for their extensive work in drafting various versions of the Task Force's report. Their untiring efforts to capture our rambling consensus on paper provided immeasurable help in keeping the Task Force moving toward a deadline that always seemed too near. SRG also secured and administered the funding from the Carnegie Corporation on behalf of the Task Force.

Rich Eiswerth of National Public Radio (NPR) served as Recording Secretary for our meetings. His work was notably helpful, but may prove even more so in the future if an historian decides to look back on what was done. Ted Coltman of CPB provided significant assistance to the Task Force with research help, both new and revisited.

Many others helped the Task Force move toward its final report. The stations provided too many good ideas, deep concerns, and difficult questions. The regional organizations provided scheduled times in busy agendas and a forum for gathering data. National organizations did likewise, as well as providing representatives to serve on the Task Force.

The Task Force appreciates the help of Jaquelyn Nixon of NPR and Salvina Cappello of CPB with respect to audience research, Jeff Tellis and John Murphy of the Intercollegiate Broadcasting System (IBS) for their vigilance in keeping the Task Force aware of the concerns of their member stations, and Rich McClear who represented Alaska Public Radio Network at several of our meetings. We also thank Alma Long at NPR, who helped with meeting logistics, and Rebecca Hartman of CPB, who helped with logistics and took care of our needs during several meetings at CPB. I'm certain that not all who helped have been named here, but to all the others – your help is appreciated.

The opportunity provided by the timing and interest in this issue is rarely found or recognized. The opportunity exists to have a full, robust discussion within the public radio system, and then build unanimous support for the result. Rarely has any subject in public broadcasting had the chance for unanimous support and none has achieved it. We hope to start a new trend toward consensus and broad support of important system issues.

DALE K. OUZTS
*Chairman*

# SUMMARY

**Public radio has emerged as a vital information resource for our nation and a fundamental institution in American culture. By embracing a wider universe of stations, producers, and supporters, and by reaching broadly across the diversity of our multicultural society, public radio can fulfill its early promise and expand the initial vision of service to the American people.**

We see a public radio system of nearly 600 stations by the year 2000 – major producing stations, scores of full-service stations that present a mix of local and national programming, operations on a smaller scale that extend the reach of the national networks, and dozens of repeater facilities that take public radio into outlying areas. We see a weekly audience of 20 million listeners.

**Goals.** Four goals for public service encourage an accelerated effort to continue public radio's growth:

- *Achieving full national coverage* – we believe it is possible to reach 95 percent of the population by 2000, a 10 percent increase in coverage to a level of service now enjoyed by public television.
- *Increasing the effectiveness of existing stations* – by improving the quality, presentation, and scheduling of current programming, and developing new "centerpiece" programming, we believe current stations can increase their weekly audience by 35 percent.
- *Realizing greater efficiencies from current resources* – by bringing additional stations into the public radio satellite network, public radio can increase the efficiency of national programming investments, reach a significant number of new listeners, and spread national programming and interconnection costs over a larger base of stations.
- *Enhancing the diversity of the audience* – with a disciplined and sophisticated programming strategy, including new programming streams and multiple stations in larger communities, public radio can reach more broadly into society and serve listeners now at the periphery of public radio's audience.

**Recommendations.** Our expansion strategy is premised on protecting and sustaining the accomplishments of the past twenty years. The greatest resource for public radio's future is the system already in place – the more than 300 stations that now reach 85 percent of the population, that raise $225 million in nonfederal support, and that serve 13.3 million listeners each week with local and national programming of the highest quality.

Building on this foundation, we have developed recommendations for a variety of national efforts to expand public radio's service. The central theme is a focus on public radio's capacity to serve its audience. We sought to move from a tally of new stations or a compilation of coverage to a plan that best brings public radio programming into the lives of as many Americans as possible.

- Existing stations and producers must be strengthened with continued investments in core programming, facilities, training, research, and promotion.
- The system must be enlarged through wider participation in the satellite network, new signals for unserved areas, assistance for stations that are upgrading to full-service standards, and limited financial support for stations pursuing public service objectives on a more limited scale.
- The system must be diversified through research to identify new service niches for public radio, major new streams of programming, and special support for minority stations.
- The expansion effort must be guided and enhanced by the evaluation of public radio's evolving audience, studies to target communities for additional service, regulatory action to increase spectrum efficiency, new training initiatives, outreach to generate needed support in the public and private sectors, and ongoing coordination of national and local activity.

**Costs.** Not all of the Task Force recommendations require major new funding. Some can be implemented at little cost. Others can be initiated with modest diversions of existing funds. But if the continued growth of the current system is to be protected, the broad vision of a larger, more diverse public radio service will be realized only with new resource commitments from America's public and private sectors.

Our estimates of funds needed to implement our recommendations over the next five years include $11.2 million for station support grants, $3.6 million for new initiatives in research, training, and system-wide projects, and $1.6 million to expand the satellite network. The most costly recommendations are for new national programming, which require up to $46.5 million over the next five years.

# I. CONTEXT

The Public Broadcasting Act of 1967 called for a national system of public radio stations to serve the entire country. Congress envisioned a partnership of federal support and local initiative to construct and sustain a diversified system of independent, noncommercial stations serving their communities with local and national programming of the highest quality.

In 1970, the Corporation for Public Broadcasting (CPB), created by that legislation, launched the nation's modern public radio system with its first grants to noncommercial, educational stations. CPB's initial grants were claimed by some 80 stations, too few to reach a large portion of America. The stations were seriously underfunded, collectively generating only $10 million in state and local support. Most stations broadcast no more than 12 hours a day, made do with two or three employees, and, together, served fewer than 2 million listeners per week.

The physical construction of a nationwide system was supported through a federal facilities grant program, initially located at the Department of Health, Education and Welfare, and now a part of the National Telecommunications and Information Administration (NTIA) within the Department of Commerce. Beginning in 1969, federal matching grants have paid a major portion of the hardware costs for public radio stations nationwide.

The past two decades have been a remarkable story of growth in public service. CPB now supports more than 300 stations that make programming available to 85 percent of the country. Stations have developed full-service schedules, built professional staffs and volunteer support, and raise $225 million in nonfederal funds that, with $60 million in federal support, fuels their efforts.

A satellite network delivers an outstanding repertoire of programming from National Public Radio (NPR), American Public Radio (APR), and scores of stations and independent producers. This national material, together with the local programming that constitutes the majority of most station's schedules, comprises a service of increasing quality and effectiveness. By early 1989, public radio each week served one listener in fifteen, 13.3 million Americans in all.

For all that has been accomplished, many of public radio's aspirations have yet to be achieved. Millions of listeners still have no access to a public radio signal. Where public radio is available, millions more find that current programming does not speak to their needs, interests, and tastes. Those who do listen are concentrated in relatively narrow segments of our society.

Much of public radio's national programming goes unheard in many communities – there is just not enough time on one or two station's schedules in which to place it. And without a critical mass of outlets, programs that have been launched with major public and private sector grants are at risk as they seek to make a transition to long-term station-based support.

At the local level, most stations have only begun to realize their potential for community service, for engagement and true impact in social and cultural affairs. Many are still far short of the skilled staff and fiscal support needed to produce and present programming that consistently meets their own high expectations.

Looking ahead, public radio is entering the 1990s with substantial momentum for expansion and growth already at work. Without a single change in current policy, at least 50 additional stations are likely to qualify for the Corporation for Public Broadcasting's Community Service Grants (CSGs) over the next ten years. Another 50 stations are likely to affiliate with public radio's national programming organizations and become a part of the satellite interconnection system.

Less certain, but also highly probable, is continuing growth in the number of people served by public radio, largely through the efforts of existing outlets. For the past several years public radio has given special attention to audience growth, and such efforts will remain a high priority for system investment for several years to come.

Finally, natural market forces will lead those stations in communities served by two or more public stations toward differentiation in their programming, from which some diversification of audiences will follow.

This growth and diversification would be no small accomplishment. The fact that such growth would occur under current policies reflects the strength and vigor of the nation's public radio system.

We believe that public radio can do more than let momentum take its course. With close attention to shared goals, modest changes in funding and regulatory policy, and additional resources from the public and private sectors, public radio can shape and accelerate its growth to more fully realize the expectations of the Congress and the public radio system itself, and speed the provision of service to a broader segment of the American people.

## WHAT IS EXPANSION?

The first issue for the Task Force was to outline the scope of our inquiry, to define, in effect, what public radio expansion means for the 1990s.

Public radio's expansion efforts have traditionally been driven by a combination of Congressional interest in extending signals to unserved areas and in minority participation, and pressure from stations outside the Corporation for Public Broadcasting's CSG program that hoped to share in CPB's annual support. As a consequence, for almost two decades, public radio expansion principally translated as starting new stations, upgrading the signals of existing outlets, and bringing additional stations into the CSG program.

The current expansion initiative clearly echoes these traditions. But it also introduces new themes that reflect several important developments of the past few years.

In 1986, public radio focused its collective attention on efforts to increase the size of its national audience. The Radio Research Consortium, National Public Radio, and other national organizations called on stations to give high priority to a wide range of audience building efforts, and CPB devoted significant funds to the effort. The audience building effort has since touched almost every aspect of the public radio enterprise, from individual station scheduling to national programming investments. It was a central theme for the Task Force as well.

In 1987, public radio restructured the financing of its national programming. Millions of dollars that CPB had invested at National Public Radio were redirected to stations. Stations, in turn, took principal responsibility for financing NPR and other national programming. The shift to "grass roots" program financing encouraged stations to give close attention to the effectiveness of national programming, to the economies of shared investments, and to the benefits of spreading costs over a larger base of stations. It also gave national producers a strong incentive to increase the number of stations that are able to carry and pay for their programming.

In 1988, *Audience 88*, a comprehensive study of public radio programming and its audience, highlighted the linkage between specific kinds of programming and specific kinds of listeners. *Audience 88*'s findings suggested that if public radio is to reach new audiences, it will need new programming. *Audience 88* also underscored the benefits that accrue to stations that present programming with a consistent audience appeal – listeners listen longer and more often, they find the station more important, and they are more likely to support it financially. The extension of that analysis is that service to a variety of audiences can best be accomplished through several stations, each consistently serving a distinct audience segment.

The confluence of these developments – the emphasis on audience building, the new approach to financing of national programming, and *Audience 88*'s strategic implications – led the Expansion Task Force to a new definition of radio expansion. The central question, stated at the broadest level, is how, over the next decade, can public radio substantially increase the number and diversity of Americans it serves. In this framework, the traditional approach of building new stations and awarding more CSGs competes with many other options.

How does public radio most effectively increase the number of its listeners? By bringing new stations into the system? Through audience building efforts at existing stations in major markets? By finding additional stations to carry its best programs? By developing new "tentpole" programs?

How does public radio foster a more diverse audience nationwide? With an emphasis on more diverse station ownership and control? By concentrating on the geographic location of stations? With alternative national programming?

These are the questions that must be addressed in this broader formulation of the expansion issue. The Task Force worked at the level of national policy and initiative, rather than individual station problem-solving. We considered the financial feasibility of various options, and how a decision to invest in any particular option would affect the system's capacity to undertake other ventures.

## WHAT IS THE PUBLIC RADIO SYSTEM?

The Federal Communications Commission has licensed 1400 noncommercial, educational radio stations. While Congress has defined all of these stations as "public radio," there are several major categories within the field:

- Some 400 noncommercial stations are devoted to religious broadcasting.
- Another 400 are operated principally by and for college or high school students, much like a student newspaper.
- Over 600 stations provide a nonsectarian service for the general public.

Most discussions of public radio, including the Task Force's inquiry, center on a subset of the latter group. For most of public radio's history, "the system" has meant a group of stations with a number of characteristics in common. They qualified for CPB's annual support grants. They received construction grants from the federal facilities program. They participated in public radio's interconnection system. They were members of NPR. They called themselves public radio. With a few exceptions, a station that had one of these traits had all the others, too. The terms CPB-qualified, NPR member, and interconnected station were essentially interchangeable and all synonymous with "the system."

As public radio has evolved, the constituencies with these key characteristics have ceased to line up in neat, congruent fashion. It is ever more difficult to define "the system" in simple terms. Nearly a fifth of the stations that qualify for CPB support are not members of NPR. Over a dozen stations participate in the interconnection system but do not receive CPB's grants. National Public Radio, American Public Radio, and the National Federation of Community Broadcasters each brings together stations both inside and outside many of these categories. For example, NPR and APR programming is heard on more than 130 stations that do not receive direct CPB support.

We must tear down the old mental walls that once rigidly divided those "in the system" from those who were not. Concurrently, we must craft new distinctions, reflecting different capacities and opportunities for public service in a changing public radio environment, that can guide future policy.

We have concluded that the public radio system of the future will be an increasingly diverse universe of stations, producers, and national organizations that share a broad commitment to public service programming for a general audience. At the same time, there will continue to be important differences among the stations and producers that comprise this larger, more loosely defined "system" – in terms of eligibility for funds, rights to programming, access to decision-making bodies, professional standing with peers, and assumptions regarding commitment to the public radio enterprise.

## SETTING SERVICE GOALS

We affirm the high priority that public radio has always assigned to the goal of near-universal signal coverage. Recent studies by the National Telecommunications and Information Administration and the Corporation for Public Broadcasting helped us identify the remaining targets for coverage.

There are currently two types of populations without a public radio signal. A substantial number of people live near major population centers in which the lack of a signal is directly related to the lack of spectrum space. Other people live in sparsely populated areas which are difficult to cover from distant locations and which are unlikely to generate adequate operating funds locally. Creative technical and financial approaches are needed to assure coverage of these areas.

The more complex service issue is that signal coverage does not mean the service will be used. Public radio is like other social and cultural institutions, such as libraries, museums, and public concert series, which are available to the entire public, but which are used by only a portion of the population.

While acknowledging the limits on public radio's capacity to serve, as noted above, the Task Force continually returned to the objective of not only enlarging, but also diversifying public radio's reach into society. Our central strategy is one of multiple services, delivered through multiple stations in the country's major population centers.

The public radio system has already surpassed the number of stations needed to deliver a single service nationwide. But it has not yet reached the level that will sustain two or more distinctive services. If the Task Force recommendations are fully implemented, achieving that capacity will be one of the major results.

We did not adopt specific audience targets, but we believe it is especially important to develop programming that appeals to America's different racial and ethnic groups. This theme should be a dominant factor in public radio's investments over the coming decade. While public radio has had limited success with respect to minority service, it has great prospects for improvement.

## PUBLIC RADIO'S MISSION

With the emphasis on audience growth, the exploration of new strategies for service, and the rethinking of "the system," the Task Force needed to address whether we also believed public radio should reassess its basic mission. We emphatically reaffirmed public radio's historic commitment to an educational public service: programming of quality and significance that challenges listeners and enriches their lives with in-depth information, the best of our nation's culture, and a responsive reflection of community and national concerns.

There are limits to public radio's reach that are implicit in that commitment. There are many in our society who will find that such a service, however implemented, has no interest or appeal. We accepted those limits, and set aside proposals that were defined principally in terms of serving groups for which public radio currently has little or no appeal.

Even so, the Task Force heard eloquent testimony to the opportunities that exist for public radio to realize its mission more fully through serving a more diverse audience. While remaining loyal to its mission and the important distinctions between public and commercial radio, there are many ways in which public stations can shape and refine their programming to make it more accessible and appealing to listeners now at the periphery of their audience.

# II. OPPORTUNITY

An accelerated effort to continue public radio's growth provides the opportunity to realize four public service goals:

- Achieving full national coverage.
- Increasing the effectiveness of existing stations.
- Realizing greater efficiencies from current resources.
- Enhancing the diversity of the audience.

## FULL NATIONAL COVERAGE

A significant portion of the U.S. population, about 15 percent, receives no public radio service. These listeners cannot receive a signal from any of the stations that are supported by the federal investment in public radio, or that are members or affiliates of one of public radio's major national organizations. Through a mix of new full-service stations, repeater stations, and translators, public radio must continue its efforts to assure that service is available to as many Americans as possible.

We believe public radio will achieve coverage of 90 percent of the nation over the next decade, assuming continuity of current efforts. With a sustained, system-wide commitment and full implementation of the recommendations in this report, it may be possible to reach 95 percent of the population by 2000, a level of service now enjoyed by public television.

In some areas, "first service" will be achieved through upgrading the staff, programming, and facilities of existing noncommercial stations to public radio's professional standards. Indeed, in a few cases this is the only currently feasible path – technical factors preclude establishing a new station. In most unserved areas, however, a new signal will be required.

We believe only a limited number of independent, full-service stations will be established in currently unserved areas. Instead, further coverage expansion will principally be accomplished through power increases for existing stations or rebroadcast of existing signals via repeater stations, Rocky Mountain Alternative Stations (repeater stations with some local origination), and translators.

There is a special urgency to this effort. The spectrum space needed for additional service is rapidly disappearing in many parts of the country. Interference protection required for Channel 6 television (which operates on frequencies adjacent to public radio) limits full use of the noncommercial band. An explosion in religious broadcasting stations, many of which are licensed on noncommercial frequencies, is consuming full-service channels at a rapid pace. A recent regulatory change, allowing creation of translator networks fed by satellite signals, will claim still more frequencies.

There is also a special challenge. Many of the areas still without a public radio signal are sparsely populated, without established organizations to develop a station, and with limited financial resources to support construction and operation. Public radio must move forward with especially careful attention to creative and cost-efficient solutions for additional coverage.

## EFFECTIVENESS OF EXISTING STATIONS

While much of the growth in public radio's audience service has come from adding stations to the system, even more has come from the increased effectiveness of existing stations. From 1979 to 1989, the number of CPB-supported stations increased by 58 percent, but the number of public radio listeners grew by 271 percent. The average station's weekly audience grew from 25,000 to 43,000.

Many factors contributed to this increased effectiveness, including increases in power and other technical improvements, the introduction of high-impact national programs, the focusing of local program schedules, the sophisticated use of audience research and program evaluation, creative promotion and community outreach, and an overall increase in the professionalism of the enterprise.

As a maturing field, public radio cannot expect to duplicate the spectacular growth of the past decade – many of the most powerful and cost-effective solutions have already been applied. We are convinced, however, that there are numerous opportunities to strengthen and refine current services and further extend the effectiveness of the existing system.

Research prepared for the Task Force highlighted a number of communities in which public radio appears to be "underperforming" compared to audience service elsewhere in the nation. While these findings were only tentative and require further analysis, they point the way to targets for major growth.

By vigorously pursuing those things public radio does best, and investing in doing them better, we believe public radio can, over the next decade, increase the weekly audience for *current* CPB-supported stations by about 35 percent.

Attaining this increase will require an average annual growth rate of about 3 percent. Part of this increase will be driven by population growth, particularly in the 35-to-55-year-old age group for which public radio has its strongest appeal. Part will come as stations achieve a share of overall radio listening, throughout the day, that matches the better hours of their current schedules. And part will come from a number of stations, including several in major markets, that have no "centerpiece" programs to anchor their service, and that are still in the early stages of their audience development.

None of this will happen automatically. Public radio will face increased competition for listeners' attention, both from other radio stations that will follow the aging "baby boom" into areas of public radio's traditional audience strength, and from the ongoing proliferation of electronic information and culture. Public radio growth requires continued investment in the effectiveness and productivity of its programming, facilities, and promotion.

## EFFICIENT USE OF RESOURCES

About one fifth of public radio's resources is spent on national programming. The dollars are about equally divided between fees paid by stations and grants from CPB, foundations, and the business community.

This investment now realizes only a portion of its potential. The average public radio station devotes 45 percent of its schedule to nonlocal programming – some 3,400 hours per year. But producers are now generating over 30,000 hours of national programming. All but the most successful programs enjoy only limited carriage. Most national programming is carried by less than half the stations that have access to it, and much of that is scheduled in off-peak hours.

Station programmers note that only a limited number of the multitude of programs available are truly compelling. Some are quickly rejected on the basis of quality. Some are passed by because acquisition fees are out of reach.

Other programming is of clear quality and little or no cost, but still receives limited carriage because it is inconsistent with the programming mission or audience target of most stations currently participating in public radio's satellite distribution system. As stations have sharpened their purposes and focused their programming, more and more programs are rejected for this reason. Further, a large body of excellent programming is not aired in many communities for no other reason than that the supply of programming exceeds the capacity of stations to deliver it – by a dramatic margin.

We believe there are at least 100 noncommercial stations that do not now participate in public radio's satellite network, that do not repeat the signal of an interconnected stations, and that have an interest in making public radio's national programming available to their audiences. Many of these stations are targeted to serve listeners now at the margins of public radio's audience.

By bringing these stations into the public radio program marketplace, public radio can increase the efficiency of its shared programming investments, reach a significant number of new listeners, and spread national programming and interconnection costs over a larger base of stations. To the extent programming costs are paid by underwriting, the public service return for such investments would grow, and the investments themselves would be more attractive.

Similar efficiencies, on a smaller scale, are possible in other areas of national activity – research, training, and national representation – where there is an opportunity to apply relatively fixed costs to a broader universe of stations.

## AUDIENCE DIVERSITY

Public radio reaches people in all parts of our society. Like all other stations on the radio dial, however, public radio has a special appeal for certain segments of the listening audience, while evoking almost no interest among others.

Audience research has repeatedly demonstrated that the principal factor separating public radio's listeners from nonlisteners is education. It is most certainly not just education itself that makes the difference. Rather, some combination of knowledge, shared experience and values, acculturation, and qualities of mind – all of which are associated with the pursuit of education – leads people to public radio's special mix of in-depth journalism, classical music, jazz, folk music, and other programming.

In American society, education is associated with many other factors, including occupation, income, race, age, and gender. As a consequence, public radio's audience, compared to the nation as a whole, is more likely to work in white-collar occupations, is more affluent, has a larger proportion of whites, has more 35-to-55-year-olds, and has slightly more men than women.

We believe public radio has the opportunity and the responsibility to reach more broadly into our society. This goal will not be realized through the expedient addition of scattered programs targeted for a variety of constituencies. Nor will it be accomplished by lowest common denominator programming that attempts to "broaden" the audience in some generic fashion. Instead, public radio must develop a disciplined and sophisticated strategy based upon an understanding of how listeners use the radio medium and a continuing commitment to excellent programming.

Most radio listening reflects the habitual use of a limited number of stations from which the listener expects a consistent, reliable service that meets his or her needs and interests. Most listeners do not seek out specific programs on stations to which they do not normally listen. Of the dozens of choices available in most communities, the average listener will tune in but three stations a week.

Conversely, when listeners confront programming not to their taste, they are quick to tune elsewhere. When they encounter such programming on a regular basis, they are likely to drop the station from their listening repertoire.

Public radio stations can work against this pattern, as many have done, but at the cost of limiting the number of listeners they might otherwise serve. We believe a strategy for audience diversity must be based on station diversity – different stations that serve different kinds of listeners in a consistent fashion.

Public radio has programs that, by themselves, appeal to groups outside the mainstream of the current public radio audience. But they are presented as part of an eclectic program mix. While some listeners tune in specifically for such programs, they are principally heard by those listeners to whom the eclectic mix itself is appealing – public radio's core audience.

By reorganizing currently available programming, both local and national, into coherent program streams with a consistent, reliable appeal to specific audiences, public radio will substantially strengthen its appeal to many groups now at the fringe of the audience. This does not mean doing the same thing all the time; it does mean doing things that appeal to the same kinds of people all the time.

This strategy of multiple service streams with consistent internal appeal is compatible with the marketing strategies of the broader American radio industry and akin to the segmentation of American higher education, in which so much of public radio has its roots.

To implement this strategy, public radio will require multiple stations in population centers throughout the nation.

Further, we believe a strategy for audience diversity will ultimately need to go beyond reordering current programming and provide for the development of major new programming that can anchor service for new audiences – much as *All Things Considered*, *Morning Edition*, and *A Prairie Home Companion* have defined so much of public radio's success to date.

Again, the effort must be disciplined and sophisticated. Public radio operates alongside more than 9,000 commercial stations that have most of the spectrum space, most of the money, and most of the listeners. Whatever public radio's aspirations and accomplishments, its role will be to fill a special niche within a larger broadcasting enterprise. The development of new programming in search of audience diversity must be based on clear and specific targets, must meet needs not addressed adequately by the commercial marketplace, and must be consistent with the broad mission and role of public radio.

Our pluralistic society offers many dimensions across which public radio might seek to diversify its audience. We believe the most compelling challenge in the coming decade is to respond to America's diversity of race and ethnicity, and that public radio can achieve a national audience that matches the racial balance of the nation.

## CRITERIA

The goals outlined above can be translated to a number of criteria that were used to shape the Task Force's recommendations to increase the reach, quality, and diversity of public radio's public service for the American people. These criteria should serve, as well, to evaluate additional plans and recommendations that are certain to come forward after the Task Force's work is done.

- **Audience Service.** Encourages greater use of public radio – more listening by more people – and enhances the importance of public radio's programming to those who listen.

- **Funding.** Protects and strengthens public radio's financial support – from individuals and private and public organizations – through opportunities for greater and more efficient investments.

- **Technology.** Preserves and extends public radio's technical capacity through continued leadership in technical quality, innovation, and creative use of existing technology.

- **Regulation.** Fosters a statutory and regulatory environment that facilitates full technological and programmatic use of the radio medium for public service objectives.

- **Fairness.** Ensures an effective distribution of services to the general public and an appropriate allocation of funds and support among the many entities within the public radio enterprise.

- **Diversity.** Encourages public radio, as a whole, to reflect our multicultural society and to serve an audience that reflects the racial and ethnic composition of our population.

- **Significance.** Advances public radio's role as a significant institution in the political, cultural, and intellectual life of our nation and its communities.

# III. RECOMMENDATIONS

**We see, by the year 2000, a public radio system of nearly 600 stations that serves a weekly audience of 20 million listeners and takes a leadership role in American life. We recommend strengthening existing stations and programming, developing new streams of programming, extending participation in public radio's satellite network, helping additional stations qualify for CPB's support, expanding signal coverage, and new initiatives in training, research, and spectrum management.**

As we look ahead to public radio's third decade, we see the opportunity to fulfill the early promise and to expand the initial vision of public radio's service to the nation – to build on the foundation of past successes, to preserve the momentum of growth, and to realize a strengthened and enlarged public radio system that is a truly significant resource for the American people.

We see a system of nearly 600 stations – major producing stations that serve both their own communities and the nation, scores of full-service stations that present a mix of local and national programming, operations on a smaller scale that extend the reach of the national networks, and dozens of repeater facilities that take public radio into outlying areas.

We see, by the year 2000, a public radio system that reaches an audience of 20 million people each week – by maintaining a superior service for current listeners, by introducing public radio to a new generation, and by reaching an audience that reflects our multicultural society.

Most important, we see a public radio system that has moved confidently from its origins at the periphery of American society to a position of leadership in the social, cultural, and informational life of our nation and its communities.

In this section we will review the strategic framework of our plan for public radio expansion, present 20 specific recommendations for national action, and discuss in further detail our proposals concerning CPB's station grant programs.

# STRATEGIC FRAMEWORK

The Public Radio Expansion Task Force has shaped a broad strategy for the coming years that reflects public radio's public service ambitions and that provides continuity for existing efforts and the listeners who depend upon them. Moreover, our approach addresses the aspirations of those ready to pursue new initiatives and the needs of audiences public radio has yet to reach.

**Protecting Current Resources.** Any plan for expanded public radio service must first assure that we protect the accomplishments of the past twenty years. Our greatest resource for public radio's future is the system already in place: stations, producers, and a distribution network that have been supported with public funds and that constitute public radio's major national organizations; hundreds of professionals who staff these efforts with skill, creativity, and dedication; and thousands of individuals who support them with their time and contributions.

Under even the most dramatic expansion scenarios, the current system will account for the vast majority of public radio's service to listeners throughout the coming decade. Enthusiasm for new endeavors must not diminish the attention and support that are needed to sustain public radio's current efforts.

**Strengthening Existing Service.** The existing public radio system has not yet realized its full potential. We believe that continued investments in core programming and the system's extensive technical infrastructure, ongoing training and professional development, and regular research and evaluation of local and national programming will yield substantial returns in additional public service.

As the public radio system matures, responsibility for these investments increasingly falls upon the stations, which now control over 90 percent of public radio's combined federal and nonfederal funds. At the same time, additional public and private funds can help stations move from maintenance to growth, especially in such areas as start-ups for new national programming, major capital projects, curriculum development for training programs, and national audience research projects that fall outside the interests of a specific network or producer.

**Developing New Initiatives.** A number of initiatives that reach beyond existing stations and programming will accelerate public radio's growth in audience service. The Task Force recommends a major investment in new programming to increase the diversity of public radio's audience, an expanded satellite interconnection system to extend the reach of national efforts, and new mechanisms to support stations that face special challenges in serving minority communities. We recommend continuing efforts to increase the population that can receive a public radio signal. We propose that CPB restructure its annual station support, helping some stations upgrade to full-service operations and supporting program acquisition for other stations that will continue to operate on a smaller scale.

**Changing Our View of the System.** Beyond these changes in programming, hardware, and funding, public radio must change its own self-perception. We envision a public radio system that is no longer defined solely in terms of those who garner a specific grant from CPB, or that affiliate with a particular organization; that is instead shaped as much or more by a shared mission of public service and participation in the rich and expanding marketplace of quality programming.

Public radio can expand its public service partnership to embrace a wider universe of stations, producers, and supporters. It can incorporate new models for delivery of programming and new models for the programming itself.

**Focusing on the Audience.** The unifying theme to all these points is the focus on public radio's capacity to serve its audience. The Task Force has moved from a tally of new stations and a compilation of coverage to a plan that best brings public radio programming into the lives of as many Americans as possible.

## THE TASK FORCE RECOMMENDATIONS

The Public Radio Expansion Task Force encourages a broad-based effort by public radio stations, their national organizations, and those who support them to implement the following recommendations.

### *Programming*

☐ Strengthen existing and develop new programming that is central to public radio's current appeal through ongoing research, evaluation, and refinement, and with such additional investments in production and acquisition as are needed to better serve public radio's current listeners and those like them.

☐ Develop one or more new, economically viable programming streams that can attract a substantial audience and that will increase public radio's audience diversity through stronger, more consistent service to listeners now at the periphery of the audience.

☐ Continue financial support for innovative efforts to increase local audiences, including the development and application of audience research, creative promotion and outreach strategies, and experimentation with formats, scheduling, and presentation.

*Funding*

- ☐ Develop a "step up" program through which stations may initially qualify for limited support from the Corporation for Public Broadcasting under a reduced version of the criteria employed for Community Service Grants, CPB's basic annual station grants. Require such stations to upgrade to prevailing qualification levels to retain support.

- ☐ Provide funds for acquisition of national programming to stations that meet the service requirements for the Corporation for Public Broadcasting's Community Service Grant (*e.g.*, full-time operation, programming for the general public, nonduplication of other CPB-supported stations), that use the public radio satellite interconnection system, but that do not have the staff, budget, or facilities to qualify for regular grant support.

- ☐ Develop a mechanism, financed by a combination of public radio funds and funds from other sources, to provide ongoing financial support to minority controlled stations that meet the service requirements for the Corporation for Public Broadcasting's Community Service Grant (*e.g.*, full-time operation, programming for the general public, nonduplication of other CPB-supported stations) but do not have the staff, budget, or facilities to qualify for regular grant support.

- ☐ Encourage NTIA's Public Telecommunications Facilities Program to make greater use of its option for planning grants with respect to system expansion.

*Interconnection*

- ☐ Extend participation in the public radio satellite interconnection system by providing funding of additional downlinks through NTIA's Public Telecommunications Facilities Program. NTIA should give more emphasis to "downlink only" projects. The target for this effort is some 100 college and community stations that have a commitment to public service programming, an interest in public radio's national programming, and sufficient professional staff and resources to integrate such programming into their local schedules.

- ☐ Examine the overall financing plan for operation of public radio's satellite-interconnection system, with particular attention to changes in fees and policies that would encourage the widest and most efficient use of the system by public radio broadcasters.

*Extension of Signal and Service*

☐ Provide technical assistance and planning support to individual stations in the design, funding, and implementation of projects that will extend public radio signals to unserved areas. While some projects will lead to new, full-service stations, most new "first service" will be accomplished by extending existing signals through repeaters and translators. Such support should encourage "Rocky Mountain Alternative Stations" (which combine unattended rebroadcast operations with local origination), the development of "local access translators," and other flexible and innovative service solutions.

☐ Identify communities that are likely to support one or more new public radio services, including:

- Communities with no CPB-supported station that might support one;
- Communities with no public radio service that might sustain the importation of a signal via repeaters or translators;
- Communities in which an existing CPB-supported station might be complemented by an additional outlet; and
- Communities in which a minority-oriented station would be especially appropriate and feasible.

Such a plan should be based on realistic projections of audience service and financial support, and developed in consultation with existing stations.

*Personnel Development*

☐ Strengthen and maintain ongoing training programs for public radio's professional staff, targeting such training on priority areas identified through periodic system-wide studies. Such training should address all skill levels, sharpening the skills of top-line staff and providing an upward career path within public radio for newer employees.

☐ Develop new training initiatives to address special needs associated with accelerated growth and diversification of the system. New and upgraded stations will bring with them talented, enthusiastic, but largely inexperienced and untrained public broadcasters. Achieving greater audience diversity may require different approaches and skills from those employed in public radio's current service. Enhanced service for minority listeners will require efforts to recruit and train minority personnel.

### *Audience and Technical Research*

☐ Develop audience research to identify alternative service niches for public radio, especially in larger markets, and to identify the broad outlines of a service strategy to fill such niches.

☐ Provide periodic research assessments of public radio's audience(s). As the public radio system expands and diversifies, such research must cut across networks and formats to provide a true overview. It must highlight specific sub-groups of stations to track the success of increased audience targeting.

☐ Convene a working group of system engineers to identify, develop, evaluate, and implement testing of new or alternative modes of mass delivery of digital programming.

### *Regulation*

☐ Encourage the Federal Communications Commission and other parties to protect and enhance the spectrum available for public radio stations serving the general public and to encourage the most efficient use of such spectrum.

☐ Develop a proposal for the Federal Communications Commission to initiate a proceeding in which it would explore reassignment of frequencies in a selected list of major markets in which there is especially inefficient use of the noncommercial spectrum and a shortage of full service facilities.

### *Outreach*

☐ Aggressively publicize public radio's shared plans for additional service – including key expansion strategies, audience targets, cost requirements, and realistic timelines. Give special attention to organizations and individuals outside public radio that have, or might be encouraged to develop, an interest in support of public radio expansion efforts – foundations, media advocacy groups, political figures, etc.

### *Follow-Up*

☐ Establish an independent, ongoing working group to monitor and coordinate the system's progress toward expansion goals. This group should be jointly convened by public radio's national organizations and should include system representatives.

# CPB STATION SUPPORT

The Corporation for Public Broadcasting's two principal station grant programs, Community Service Grants and National Program Production and Acquisition Grants (NPPAGs), were the focus of many of the proposals we considered. Because CPB's station support is so important – both to the stations that now receive it and those who seek it – we will discuss our recommendations in this area in further detail.

Both CSGs and NPPAGs require a station to provide a certain minimum level of service, measured by budget, staff, signal strength, hours of operation, studio capacity, and a number of other criteria. The size of a station's grant is based on a match of its nonfederal financial support.

The approach embodied in the CSG and NPPAG programs has served public radio well. It has provided an incentive for over 300 stations to achieve basic professional standards and assured that CPB's funds are invested in responsible operations. It has provided a reward and continuing partnership for those stations that have moved well beyond these levels.

Although CPB's station support has slowly declined as a share of public radio's total income, these funds continue to play a critical role in most stations' overall financial plans. Because CSGs and NPPAGs are so vitally important to the stations that receive them, many of these stations are reluctant to enlarge the number of beneficiaries without a corresponding increase in the funds available.

Conversely, a number of stations that do not qualify for CSG and NPPAG support, and some that do, urged the Task Force to recommend revisions in the grant policies that would recognize the public service such stations provide.

**Maintaining Grant Criteria.** The Task Force received several proposals to lower the criteria for CSGs and NPPAGs – across-the-board, for particular kinds of stations or markets, or for stations that would form a "lower tier" of service. We declined to adopt these proposals. Most members felt strongly that it is important to preserve the minimum professional standards reflected in the current grant criteria.

Instead of lowering current CSG and NPPAG criteria, we designed a two-track effort that will help some stations meet the operational levels needed to qualify for the grants and provide limited assistance to others that operate on a smaller scale.

The step-up program we are recommending is a variation on an approach that CPB has used a number of times in the past – providing support to stations in early stages of development on the condition that they make progress toward full-service standards. A majority of the current CPB-supported stations first received funding from CPB when their operations were below the current minimum criteria.

**Support for Other Stations.** The Task Force identified a number of stations that provide a public service for their communities, but that are unlikely to seek support from the CSG or NPPAG programs under the current criteria. We believe there are several ways in which public radio can respond, outside the major grant programs, to the efforts and aspirations of these stations.

Our principal objective for these stations is to connect them to public radio's national programming, providing the benefit of millions of dollars worth of programming that can be made available to them at little or no cost.

The first step is to help these stations participate in the public radio satellite system, and we recommend support for one-time capital costs. The second step is to assure that, once interconnected, the stations are able to participate in the evolving programming marketplace. To this end, we recommend limited assistance with program acquisition costs, on an ongoing basis, for interconnected stations that are not otherwise supported by CPB and that meet CPB's general public service requirements.

The effectiveness of these recommendations will depend, in part, on the fees these stations encounter as they seek national programming. Since the marginal costs of an additional station participating in the satellite system or carrying a given program are limited, we hope that it will be possible to develop accommodating pricing policies for both interconnection and programming.

We have recommended an overall review of interconnection system pricing, with an eye to encouraging maximum use. We also encourage APR, NPR, and other producers and distributors, to continue their efforts to craft pricing structures that accommodate these stations' needs and fiscal abilities.

Of the stations that do not receive CSG or NPPAG support, we believe minority controlled stations face an especially difficult situation. There are approximately 35 such stations. Many of these stations provide a programming service under conditions not generally shared by the rest of the system. Most significant, these stations find only a limited amount of public radio's national programming relevant to their mission and audiences. We recommend that these stations receive a special general operating grant.

**Financial Impact.** Following the adoption of these station support recommendations in principle, we examined detailed cost projections associated with each proposal.

We did not recommend a specific source of funds for the CSG step-up program, special program grants, and minority station grants. Under current funding circumstances, however, it is likely that such efforts would be funded, at least in part, from the CSG and NPPAG pools. The statutory formula that governs CPB's use of its federal appropriation and its interest income leaves few dollars available for discretionary purposes. Use of those discretionary dollars as the principal funding source for radio expansion would require the sacrifice of other programs.

If *all* of the station support recommendations were funded from CSG and NPPAG dollars, the result would be a reduction of about 2.2 percent in the FY 1991 grants that currently-supported stations would otherwise receive.

This figure would rise in subsequent years, as the number of stations receiving regular CSG and NPPAG grants would grow at a faster rate with the help of these programs. Even so, if CPB's funds for CSGs and NPPAGs rise only at a cost-of-living rate, and if all our station support recommendations are funded with CSG and NPPAG dollars, we estimate that in FY 1995 less than 5 percent of CPB's station support funds would be diverted as a result of the special expansion effort.

The same statutory formula that would lead CPB to finance expansion out of CSGs and NPPAGs also assures that any increase in CPB's federal support beyond inflation would directly offset these costs. The formula channels 93 percent of radio's share of the appropriation directly to CSGs and NPPAGs.

For several years, in part because there are initially only limited funds to fuel the expansion effort, we believe currently-supported stations will perceive little payoff from this investment. Over the long term, however, these stations will derive important programming and financial benefits.

The growing number of stations in the public radio programming marketplace will make it feasible to sustain new programming initiatives. This will be especially true for material that is currently outside the mainstream of public radio programming, but which may be of interest to stations entering the system.

When there are multiple stations in a community, there is less pressure for any one station to cover all the needs unaddressed by commercial outlets. As a result, stations can bring more focus and definition to their service, an approach which pays dividends in audience response and financial support.

All stations will realize greater economies of scale as fixed costs for interconnection, representation, research, training, and other activities are shared by a larger number of stations. And as the newer stations mature, they will bring more listeners and dollars to the collective public radio effort, making national underwriting more attractive and bringing more resources to shared investments.

Finally, a growing system, working toward service to more parts of the country, and toward an audience that better reflects the diversity of America, will have a stronger case as it seeks a renewed and strengthened investment of federal funds.

# IV. COSTS

Some of our recommendations can be implemented at little cost. Others could be initiated with modest diversions of existing funds. But if the continued growth of the current system is to be protected, the broad vision of a larger, more diverse public radio service will be realized only with new resource commitments from America's public and private sectors.

While the Task Force considered the prospects for public radio's growth throughout the coming decade, we decided that a five-year period provided a more realistic horizon for cost projections at this time.

**Station Support Grants.** The Task Force reviewed detailed, year-by-year models of the various station support programs it is recommending, including possible eligibility criteria, grant amounts, and projections of participating stations. Our cost estimates are derived from these models, but are presented here as more generalized totals. This approach recognizes that actual expenditures will be influenced by a combination of local initiative and a variety of grant policies that are the appropriate responsibility of CPB.

The various station support programs we have recommended require $11.2 million in national funds.[1] Of this total, $8.5 million is associated with stations' accelerated entry into CPB's grant programs through the recommended step-up effort. The majority of this cost is attributable to additional Community Service Grants and National Program Production and Acquisition Grants these stations will receive once they are qualified for regular support. We estimate that 55 stations will move through the step-up program during this period.

Program acquisition support for interconnected stations outside the regular CPB grants programs requires approximately $.5 million over five years, with such support eventually reaching 30 stations. Additional support recommended for minority stations requires another $2.2 million for the 30 stations we estimate will claim such funds.

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[1] All cost estimates assume an annual inflation rate of 5 percent through the five year period.

**Research, Training, and System Support.** New initiatives in research, training, and other support activities require some $3.6 million from FY 1991 through FY 1995. About one-third of these costs are for one-time activities, such as the identification of alternative service niches for public radio, curriculum development for new training projects, and technical research on digital audio delivery. The remainder is for ongoing research, training, and consulting activities connected with expansion.

It is important to stress that this cost estimate, like the others presented here, embraces only those activities directly linked to new services and new stations. Current commitments to research, training, and other aspects of system development must be maintained to preserve the momentum and strengthen the services of the existing system.

**Interconnection.** About $1.6 million will be required in matching grants to help additional stations participate in public radio's interconnection system. This will provide up to 75 percent of the construction costs for 80 stations.

**New Programming.** The largest expense (but also the most difficult to estimate with precision) is the development of one or more new programming streams designed to increase public radio's audience diversity. Beginning with $2 million in seed money in FY 1991 and rising to $15 million by FY 1995, this undertaking will require a total of $46.5 million over the five-year period.

To put this estimate in perspective, all of NPR's news and information programming costs about $20 million per year. Garrison Keillor's 90-minute weekly variety program for APR costs about $2.5 million. Daily half-hour programs like APR's *Marketplace* and NPR's *Fresh Air* cost about $1.5 million.

**Construction Costs for Extension of Signal.** We did not estimate the construction costs for new stations and upgrades of existing stations to extend public radio's signal to unserved areas. Such projects already receive the highest priority for funding at NTIA's facilities program and total dollars available for the program are adequate to address this need.

**Finding the Dollars.** We did not develop a plan for financing these costs — or the additional resources needed to strengthen existing programming, audience building, research, and training activities. That effort, we believe, must be part of a broader financing plan for public radio over the coming decade.

It is quite clear, however, that implementation of this expansion plan will require substantial resources beyond those now available to public radio. The national investments outlined here would represent about one-fifth of the Corporation for Public Broadcasting's total support for public radio over the five-year period, assuming funding at current levels.

# V. BUILDING CONSENSUS

## Successful expansion of public radio's service depends upon the support and cooperation of the entire public radio system.

**A Representative Group.** The first step in enlisting support for the Task Force's recommendations was to assure that the Task Force itself was as representative as possible within the limits of a manageable and affordable working group. While Task Force members participated as individuals, each was selected for the variety of interests, experiences, and affiliations he or she could contribute to the inquiry.

One or more Task Force members brought to the group their personal experience with university, community, and state licensees; minority stations; stations in major markets, mid-sized cities, and rural areas (including Alaska); stations with budgets from under $100,000 to more than $1,000,000; and stations that do and do not receive regular CPB support. The Task Force included representatives of public radio's two principal funders, CPB and PTFP; representatives of four station-oriented national organizations (APR, NFCB, NPR and SRG); and members of most of public radio's regional organizations.

Members of the Task Force have worked as producers at both the local and national level, at stations and as independents. They have worked with program formats including national and local news, classical music, jazz, folk, drama, talk shows, various ethnic music, bluegrass and other genres.

**A Participatory Process.** The Task Force was strongly committed to work directly with the public radio system throughout the study. We secured a place on the agenda of every state, regional, and national meeting of public radio stations for a six month period. Preliminary recommendations were mailed to every CPB-supported station and to many other stations with an interest in the expansion effort. Eastern Public Radio sponsored a national call-in over the satellite system. We surveyed all the noncommercial stations in the country to ascertain their current levels of operations.

Meetings were open and well publicized, and were attended by many interested parties. We encouraged stations and others to communicate with the Task Force throughout the process, and many did so – in letters, phone calls, and personal appearances at Task Force meetings.

**A Continuing Effort.** We have placed this discussion of our approach at the conclusion of our report because we believe a similar effort will be needed to guide the implementation of our recommendations in the months and years ahead. In the highly decentralized American system of public broadcasting, our plan for expansion of public radio's service requires the support and participation of hundreds of entities at the national, state, and local level.

Each of public radio's national organizations must determine how it will respond to our recommendations for funding, program development, policy initiatives, training, research, and other activities to support stations' efforts. State public broadcasting authorities and state-wide networks must consider how to strengthen the services they now support while looking to those parts of their states in which public radio is still unavailable. And the hundreds of universities, colleges, community organizations, school districts, and others that hold public radio's licenses, raise most of its funds, and shape its daily service must gauge their ability to meet the challenges we have presented.

The discussion of expansion must ultimately move beyond the public radio system to enlist the support of those who can provide the resources needed to realize our goals – members of Congress and state legislatures, the business community, the leadership of social and cultural institutions, and the philanthropic community.

We recognize that the appropriate scope and most effective paths for public radio's growth are matters for continuing debate. We hope our analysis and recommendations will inform that debate, and guide it toward the most critical issues.

We believe the promise of public radio remains as fresh and compelling today as it was twenty years ago, and that the larger vision of service we have mapped in this report is broadly shared.

# U.S. INSTITUTE OF PEACE

## STATEMENT OF SENATOR SPARK MATSUNAGA

Mr. Chairman, I greatly appreciate having this opportunity to testify in strong support of the Fiscal Year 1991 budget request of the United States Institute of Peace, and I wish to thank you and the Subcommittee for scheduling these hearings on a broad range of education, health and other important programs administered by the federal Departments of Education, Health & Human Services, and Labor.

Although it hardly seems possible, the U. S. Institute of Peace will be five years old in February 1991. As the principal sponsor in the Senate of legislation to establish the Institute, and as one of a great many Americans who worked to establish a federal entity devoted to peace research, education and training, I am extremely gratified to report that the Institute has made steady progress during its first five years and is now poised to deal with the revolutionary changes which have occurred in the world in the last year and which will occur during the 1990's.

And what a change there has been! For the first time since British Prime Minister Winston Churchill made his famous "Iron Curtain" speech in Independence, Missouri after World War II, -- marking the beginning of the Cold War -- the United States has a significant opportunity to help shape a new and more peaceful world. As President Bush noted in his State of the Union Address earlier this year, the "Revolution of '89" has brought about a change so striking that it marks the beginning of a new era in world affairs. Moreover, while not entirely bloodless, the "Revolution" was accomplished largely through peaceful negotiation and elections.

Now the real work begins. As the Cold War fades into history, and meaningful arms control is accomplished, the new leaders in Europe and throughout the world will need not only peaceful economic assistance, but assistance in establishing new national institutions, in resolving intranational conflicts between ethnic and religious groups, and in settling longstanding border disputes and other controversies between nations which are likely to emerge once again.

Fortunately, the Peace Institute has many projects directly related to the new era in which we find ourselves. A few of note are its new program on Religion, Ethics and Human Rights, its plans for a conference on German reunification, its study of the future prospects of peace or conflict in Central Europe, and its study of ways to strengthen the United Nations in order to meet the challenges of low intensity conflict. These are all projects which can assist Congress and the Executive Branch as we try to address the changing world situation, and they are projects which are also of great interest to the American people -- especially those engaged in overseas business or in humanitarian programs.

I am also pleased to report that the Institute has adopted a five-year development plan (through 1994) calling for faster growth of its education, public outreach and information dissemination programs, and for continued, if slower, growth of its research arm. In both the research and public outreach areas, the Jennings Randolph Fellows are becoming an increasingly valuable resource to the Institute. There is one area that concerns me, however, and that is that the Peace Institute's appropriations have not yet reached a level that would permit it to provide larger grants on a sustained basis for institutional programs. For example, the University of Hawaii, which has established its own Institute for Peace and presently offers a certificate in peace studies, wants to establish a Master's degree program in peace studies. While it is very likely that the State Legislature could be persuaded to provide some funding for this type of program, it will require substantial and sustained support from the U. S. Institute of Peace as well. I am sure that there are other educational institutions and organizations throughout the country which, having been encouraged by establishment of the

U. S. Institute of Peace, are now ready to take on similarly ambitious and worthwhile projects.

Personally, I believe that the Institute should be funded at its full authorized level of $10 million in Fiscal Year 1991. However, I support the Institute's request for $9.2 million and believe that amount will permit some growth and development of the Institute. I, therefore, urge the Subcommittee to approve the Institute's request without any reductions.

Thank you again, Mr. Chairman, for the opportunity to express my support for the budget request of the U. S. Institute of Peace.

## STATEMENT OF THE UNIVERSITY OF HAWAII INSTITUTE FOR PEACE

The University of Hawaii Institute for Peace would like to endorse the statement of Senator Matsunaga in support of the U.S. Institute of Peace budget request and urge that full funding be provided to U.S.I.P. The U.S. Institute fulfills a symbolic and substantive role.

Symbolically, it serves as an example of our national commitment to the study of peaceful alternatives to conflict. In that regard, the meager funding it receives sends a strong message to the world--we are more willing to spend our resources on costly armaments than on the study of peace and conflict resolution.

Substantively, it funds research into the causes of war and the conditions of peace. In spite of a rather conservative Board of Directors, its agenda is not limited to strategic studies, but also includes research into the uses of nonviolence, such as the tactics used during the recent liberation of Eastern Europe. It also funds research into human rights, the role of religion an ideology in conflict, and inquiry into regional conflicts.

The University of Hawaii Institute for Peace has had a good relationship with the U.S. Institute. Recently, President Samuel W. Lewis and several others from the U.S. Institute came to our campus and conducted several workshops and symposia, which greatly enhanced our academic program. In addition, we have received several small grants from the Institute:

- Fifteen thousand dollars for the Human Rights in the South Pacific Project, which was successful in drafting a Model Human Rights Charter for the

Pacific which is now circulating among the nations of the South Pacific. It is expected that further meetings will occur at the governmental level and that a treaty will eventually be adopted.

- We also received $39,000 for our Asia-Pacific Dialogue, a unique project in which scholars from various countries in the Asia-Pacific region are brought together to discuss mutual concerns; they then return to their countries to share their new-found knowledge and insights with their colleagues and political figures. Last year, we had North Korean, South Korean scholars discussing the problems of the Korean peninsula with experts from other Asia-Pacific nations, the first time such a meeting has taken place. Enthusiasm was so high that we intend to continue this project and are planning the next meeting for August 1990.
- Mark Juergensmeyer of our University has received a $40,000 grant to study religious violence and nationalism in the Third World, focusing on Sri Lanka, the Punjab (India), Iran and Egypt.
- Michael Haas of our Institute has received a $12,000 grant to support a project on resolving the conflict in Cambodia, using the "options analysis" method to assess the various stages of conflict.
- Carolyn Stephenson has received $12,000 to help develop our curriculum program for undergraduates.

With more funding, we could increase the services we offer to our community and the Asia-Pacific region. More specifically, we need an institutional grant from the U.S. Institute of Peace to supplement the funds we receive from state and private sources. (Attached is a resolution from the Hawaii State Senate requesting such an institutional grant.) Your favorable response to the budget request could make this a reality. We have planned an ambitious program here, but are restricted in our activities because of limited funding sources. We now offer an undergraduate peace certificate and are developing a major for undergraduates. We should like to offer a Master in Peace and Conflict Studies, but need funding for faculty positions. We encourage our faculty in their peace research, and currently have awarded small grants to fourteen researchers who are working on topics such as responsible tourism; conflict resolution in the public schools; the rights of children; and religion, ecology, and social conflict on the Malay-Thai border. In addition, we sponsor frequent symposia in which our scholars and visiting scholars discuss peace and conflict issues, such as the recent events in Eastern Europe and Panama. Community groups sponsor peace events such as all-day workshop sessions, art exhibits, and dramatic offerings, and we offer them administrative support as well as small grants. With an institutional grant, we could expand these activities, and serve our community more completely.

In conclusion, the budget request from the U.S. Institute of Peace is a modest one fully deserving of the support of this committee. We support this request and would like to see more of a financial commitment to the pursuit of peace from our federal government.

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THE SENATE
FIFTEENTH LEGISLATURE, 1989
STATE OF HAWAII

MAR 22 1989

S.R. NO. 84

# SENATE RESOLUTION

REQUESTING THE UNITED STATES INSTITUTE OF PEACE TO GIVE AN INSTITUTIONAL GRANT TO THE UNIVERSITY OF HAWAII INSTITUTE FOR PEACE.

WHEREAS, humanity today faces the inescapable choice, of living together in peace, or perishing together in warfare; and

WHEREAS, conflicts involving struggles between nations and civil wars within nations are occurring in many areas of the world; and

WHEREAS, situations of social, political, economic, and cultural injustice exist in many parts of the world which are likely to lead to conflicts and violence; and

WHEREAS, the University of Hawaii Institute for Peace has been in existence since December 1985 and has developed a strong program of course offerings, research activities, and community outreach designed to address these problems of violence and injustice; and

WHEREAS, the University of Hawaii Institute for Peace has planned and proposed a Masters of Peace Studies, a two-year curriculum program designed to train professionals who will have the skills and theoretical background to address and help resolve situations of present and future conflicts; and

WHEREAS, the University of Hawaii Institute for Peace has similar curricular offerings for undergraduates to help prepare them for work in this field; and

WHEREAS, the University of Hawaii Institute for Peace has major research projects already underway in collaboration with colleagues in the Asia-Pacific region, including the Asia-Pacific dialogue which is designed to address issues dividing the socialist and nonsocialist countries of the region, the Pacific Human Rights Project which is designed to develop a model human rights treaty for the Pacific Islands community, and the Center for Global Nonviolence which is designed to promote research into the techniques and effectiveness of nonviolent action; and

WHEREAS, the University of Hawaii Institute for Peace is developing a strong community outreach program including speakers, artistic performances and events, and resource centers, all designed to help residents of Hawaii understand the issues related to war and peace; and

WHEREAS, the State of Hawaii is now providing the core funding for the University of Hawaii Institute for Peace, but additional funds are needed for it to carry out its work properly; and

WHEREAS, the United States Institute of Peace was established, in part through the commitment and work of Senator Spark Matsunaga, to address issues of peace and social justice and to ensure that these issues are examined in universities and communities across the United States; and

WHEREAS, the United States Institute of Peace is instructed to disseminate at least one fourth of its annual budget to support activities of appropriate entities engaged in peace studies, peace research, and community activities; now, therefore,

BE IT RESOLVED by the Senate of the Fifteenth Legislature of the State of Hawaii, Regular Session of 1989, that the United States Institute of Peace is requested to give an additional grant to the University of Hawaii Institute for Peace in the amount of $300,000 per annum to allow it to develop its programs properly and thus to fulfill its mission to the people of Hawaii and the Asia-Pacific region; and

BE IT FURTHER RESOLVED that certified copies of this Resolution be transmitted to the United States Institute of Peace, the University of Hawaii Institute for Peace, and the members of Hawaii's congressional delegation.

Mary-Jane McMurdo

OFFERED BY: Malama Solomon

Russell Blair

Gerald T. Hagino

Donna R. Ikeda

Mike McCartney

Richard Matsuura

RFS1143 SR SMA

Milton Holt

Ann Kobayashi

Bertrand Kobayashi

I hereby certify that the foregoing is a true and correct copy of Senate Resolution No. 84, which was duly adopted by the Senate of the State of Hawaii on April 14, 1989

Dated: April 26, 1989

Assistant Clerk of the Senate

# MISCELLANEOUS

## STATEMENT OF THE NATIONAL TREASURY EMPLOYEES UNION

Mr. Chairman and Members of the Subcommittee:

I am Robert M. Tobias, National President of the National Treasury Employees Union. NTEU is the exclusive representative of over 144,000 Federal employees, including workers in the Office of the Secretary, SSA's Office of Hearings and Appeals, Office of Human Development Services, Family Support Administration, and the ten regional offices of the Department of Health and Human Services. I am accompanied by Patrick Smith NTEU Director of Legislation, and Paul Suplizio legislative consultant.

I am pleased to appear before you to present NTEU's recommendations on the Administration's budget proposals for HHS for FY 1991. Under this budget, HHS staff will rise to 119,600 full-time equivalent positions in FY 1991 -- an increase of 1,600 positions. After a decade of "downsizing" the Department from 150,000 FTE in FY 1981 to the current level of 118,000 FTE, the Administration is calling a halt. Why? Because it has on its hands a political calamity resulting from its misguided and ineffective stewardship of this Department.

Social Security's field office delivery system is a shambles. People are not getting the help they need. Generic drug oversight at the Food and Drug Administration is a national scandal. The Health Care Financing Administration is losing a billion dollars a year from failing to bill primary Medicare insurers. Grant administration in the Office of Human Development Services and Office of Community Services is ineffectual and wasting millions. As the Subcommittee is aware, many more examples can be given, documented by the General Accounting Office and HHS Inspector General.

Downsizing has sapped the vitality of the civil service in HHS. It has overburdened our workers and ruined morale. It forced the exodus of many of the best and brightest employees. When workers are treated shabbily by their government, they lose self-esteem and pride in service. NTEU is convinced that, with the right leadership, this can be turned around. But it's ludicrous to think that with another 500 staff-years at SSA, or FDA, or HCFA, the enormous problems in the strained and overburdened agencies in HHS can be solved. The President's budget should be decisively rejected because it is not responsive to the crisis of public confidence in government's ability to carry out the programs it is charged to administer.

The Comptroller General recently told Congress: "The seemingly never ending disclosures of fraud, waste, abuse, and mismanagement in federal programs continue to paint the picture of a government unable to manage its programs, protect its assets, or provide taxpayers with the effective and economical services they expect and deserve. One has only to pick up the newspaper to read about scandals in Defense procurement activities or the debacle at the Department of Housing and Urban Development (HUD) which have cost us billions of dollars and further undermine confidence in government...The problems that exist are not limited to a few agencies or a few programs; rather, all of the major agencies have serious problems."

The Comptroller General has said that many agency problems are known, but often remain uncorrected for years . Wny is this so? The invariable answer from Federal managers and workers is that the resources aren't provided. What Federal employees ask is that Congress give them the tools needed to do their job. In SSA, billions in overpayments to beneficiaries are going uncollected from systems errors and inadequate staff. HCFA is also capable of saving billions with more staff and better systems. If agencies like SSA and HCFA were given the resources to accelerate collection of these funds and prevent errors, the additional revenue would allow HHS to staff components like HDS and FSA to meet their rapidly growing responsibilities. By saving the taxpayers' money, the Department's civil servants more than pay for themselves.

To lift HHS to a higher level of performance and prevent a collapse such as occurred at HUD, NTEU recommends adoption of a five-year action plan to invest in the human resources needed to ensure adequate staff levels and the proper mix of skills throughout the Department. This action plan would have three components.

First, each agency should be required to prepare a five-year resource plan containing workload forecasts and specifying the funds and staff requirements needed to accomplish its assigned tasks in light of the workload. The tasks to be performed will include the correction of the material weaknesses and deficiencies identified by the General Accounting Office (GAO) and Office of Inspector General (OIG).

Second, to deal with the lack of budget authority to appropriate funds for adequate Federal administration, Congress should consider authorizing a Secretary's revolving fund into which would be deposited all recoveries, civil penalties and similar collections resulting from the operations of HHS components to recover improper charges to Federal funds, overpayments, damages, and the like. HHS would be allowed to spend from this revolving fund, under a permanent indefinite appropriation, for staff requirements and other needs to accommodate new workload, tasks, or missions. If OMB objected to a planned use by the Secretary, Congress could legislate a specific number of staff-years to be paid for from the fund. Since it can be anticipated that several hundred million dollars will be deposited in the fund each year, and only a small fraction of that will be utilized, the excess in the fund would apply to reduce the Federal deficit.

Third, an alternative budget that responds to the need for Federal staff should be enacted by Congress. To assist in this task, NTEU has prepared an alternative budget with specific staff and funding recommendations for each HHS agency except the National Institutes of Health and Indian Health Service. Our recommendations are summarized in Table 1 and our justification is presented in the remainder of this statement and in an accompanying statement on the Social Security Administration.

NTEU's alternative budget would add $550 million and 7,636 FTE to the HHS budget request for FY 1991. Of this amount, $180 million is to restore program funds for the Bureau of Health Professions in the Health Resources and Services Administration. Another $200 million and 6,500 average positions are required to meet the urgent needs of the Social Security Administration, which lost the most through downsizing and has the most ground to recover to serve 55 million beneficiaries. The total cost of the additional 7,636 FTE recommended by NTEU is approximately $300 million. NTEU would add 260 positions to the Health Care Financing Administration, 200 positions to the Office of Human Development Services, and 129 positions to the Family Support Administration.

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## STATEMENT OF THE UNITED STATES CATHOLIC CONFERENCE

The United States Catholic Conference, the public policy agency of the nation's Roman Catholic bishops urges that the current hearings and decisions on the 1991 Appropriations Act provide $40 million for the Chapter 1 "capital expense" provision of Section 1017(d) of P.L. 100-297, the Augustus F. Hawkins/Robert T. Stafford Elementary and Secondary School Amendments of 1988. The lingering injurious effects of the 1985 Aguilar decision still plague the Chapter 1 program for both public and private school children.

1990 is the twenty-fifth anniversary of the Title 1/Chapter 1 Program. As you probably are aware, for over twenty-five years this program has helped countless millions of educationally disadvantaged children in both public and private schools by providing them with specially designed compensatory educational services. From its beginnings as Title I of the Elementary and Secondary Education Act, the program was designed to help educationally disadvantaged children overcome their learning difficulties, and thereby recognized that some of the children who needed and qualified for help attended Catholic and other private schools.

Since the Aguilar decision, private school students' participation in the Chapter 1 program nationwide has decreased 34 percent, from 185,000 to 123,000 students between school year 1984-85 and school year 1985-86. Although participation has since increased, for school year 1987-88 it remained at 135,699, 26 percent fewer than before Aguilar. Participation estimates provided by state education agency officials for school year 1988-89 reflect further increases to 141,000 students. But that level still is 23 percent, or 44,000 students, below the pre-Aguilar level of participation.

In 1988, Congress reauthorized the Chapter 1 program and provided help to local school districts to get this program back on track for private school children. Public Law 100-297, the Augustus F. Hawkins- Robert T. Stafford Elementary and Secondary School Improvement Amendments of 1988, authorized "capital expense" funds to enable school districts to comply both with the Aguilar decision and the provisions of the law calling for equitable participation of private school children. The new statute authorized funds - $40 million for fiscal year 1989 and "such funds as may be necessary" for fiscal years 1990 through 1993 - to pay for increased capital expenditures incurred after Aguilar for noninstructional goods and services used in providing Chapter 1 services to children in private schools. Ultimately, increased capital expense funds will mean that more funds will be available for instructional services for both public and private school children.

In June 1988, the House Appropriations Subcommittee for Labor, Health, and Human Services, Education and Related Agencies recommended an FY'89 appropriation of $30 million for Section 1017(d) the "capital expense" provision of P.L. 100-297. Unfortunately neither the Administration nor this Subcommittee made a recommendation for such funding in FY'89. However, because of the House recommendation an appropriation of $20 million for FY'89 prevailed in the House/Senate Conference. After budget reduction, $19.7 million was allocated to the states for expenditure during the 1989-90 school year. To our delight your Senate Subcommittee recommended an FY'90 appropriation for Chapter 1 "capital expense" funds of $22 million. The House again proposed $30 million. During the House/Senate Conference the total FY'90 Chapter 1 "capital expense" funding was compromised at $25.7 million. This made the total appropriation provided by Congress over the past two years at $45.5 million. However, there is still a great need for continued "capital expense" appropriations to help overcome the deleterious effects of the Aguilar decision on the Chapter 1 program for both public and private school children.

A 1989 GAO Briefing Report to Congressional Committees on the Aguilar v. Felton Decision's Continuing Impact on the Chapter 1 Program supports the need for further "capital expense" funds when it reports that:

> "Forty-six of 52 state Chapter 1 coordinators estimated that school districts have or will incur $105 million in eligible capital expenditures. These 46 states had 81 percent of the private school children in Chapter 1 before Felton.
>
> Six states were unable to provide estimates of expenditures. One was California, which before Felton served approximately 11 percent of the private school students under Chapter 1 nationwide, which presumably will add significantly to the total expenditures. The other five states combined served 8 percent of the private school students before Felton."

In sum, there are 46 states showing the need for $105 million for eligible "capital expenses." There are six states with a total of 19 percent of private school children eligible for Chapter 1 services also in need of "capital expense" funds but are unable at this time to estimate the amount.

The $19.7 million "capital expense" funds which were appropriated for fiscal year 1989 were sufficient enough to cover only 31 percent of the $63 million which states estimated that they would have expended by the end of the 1988-89 school year. The recent $25.7 million appropriated for school year 1990-91 increased the total two year appropriations to $45.5 million, but this is still well below half of the $105 million estimated to be needed by at least 46 states not to mention the six other states which have 19 percent of eligible private school children.

In addition, if the number of eligible private school children waiting to receive Chapter 1 services, as reported in the GAO study, is indeed, 40,000 below the 1984-85 pre-*Aguilar* level; then, we will continue to need the maximum appropriation of $40 million annually to meet the stated intent of Congress regarding these "capital expense" funds:

> "... to provide sufficient funding to enable local educational agencies, to the extent possible, to restore Chapter 1 services for nonpublic school children to their pre-*Aguilar* levels and quality."

Attached, Mr. Chairman, is a chart of selected states which illustrates the decline in the participation of private school children in the Chapter 1 program after the *Aguilar* decision. We wish to point out the gradual increase in the level of participation in some states and the creeping decline of such participation in other states. This illustrates our case and the need for a continuation of "capital expense" funds.

Therefore, we urge all members of this Subcommittee, to approve an appropriation of the $40 million for "capital expenses" as authorized for fiscal year 1991.

## LETTER FROM THE UNIVERSITY OF ILLINOIS AT CHICAGO

April 6, 1990

Senator Thomas Harkins, Chair
Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services
Dirkson Building 186
U.S. Senate
Washington, DC 20510

FAX# 202-224-7283

Dear Senator Harkins:

I am writing to request your support for the Administration's FY 1991 budget request of $21.0 million for the AIDS Education and Training Center program. This program was established over two years ago within the Health Resources and Services Administration of the Department of Health and Human Services. The program has statutory basis within Title VII of the Public Health Service, Section 788A.

I would be grateful if you, as a member of the Senate Appropriations Subcommittee on Health and Human Services, would submit this letter as public testimony in support of the program.

The Midwest AIDS Training and Education Center is one of fifteen regional or statewide AIDS Education and Training Centers (ETCs) which were established to provide comprehensive AIDS education to community based health practitioners (particularly physicians, nurses and dentists), to faculty within health professions schools, and to students in medical schools, nursing schools and other health programs. The AIDS ETC program utilizes the expertise of practitioners from the above schools, along with experienced caregivers in the community, to educate more health workers about HIV disease and to increase the clinical skills of those with a basic knowledge of the disease. This expansion is essential to providing appropriate numbers of health care workers for the growing number of individuals with HIV disease.

The Center has responsibility for education of health professionals in six states in the Midwest: Iowa, Illinois, Indiana, Minnesota, Missouri, and Wisconsin. Our Iowa site is located at the University of Iowa in Iowa City, under the direction of Charles Helms, M.D., Ph. D., who is an Infectious Disease Specialist and Associate Dean of the College of Medicine. Under his leadership the site has established a network of AIDS Education Instructors, tapping into an existing state-wide network of infection control nurses. In addition, the site has actively provided ongoing training of physicians through the primary care family practice residency programs throughout the state. The site provides leadership in presenting a statewide interdisciplinary AIDS conference each year and works hand-in-hand with the Iowa Department of Public Health. In the current year we expect that about 1,000 health professionals will be reached through the program in Iowa.

The Iowa program provides an example of programming in low incidence areas, where an emphasis on teaching health professionals prevention, patient and community education, as well as clinical management skills are critical. In higher incidence states like Illinois and Missouri we spend even greater time and resources attempting wide-scale health worker education.

While MATEC has made an excellent beginning in providing education to health professionals throughout our service area, we are like other ETC's in our limited ability to reach all health professionals given current resources.

During the first year when there were thirteen AIDS ETCs in operation, the following education services were provided:

Aggregate Estimates for 13 ETCs

| Provider Category | Participants Served in First Year |
|---|---|
| Physicians | 31,976 |
| Dentists/Dental Providers | 11,830 |
| Nurses | 59,537 |
| Others | 120,708 |
| Sub - total of directly trained providers | 224,051 |
| Tele-conference Audience | 150,871 |
| Total Estimate of Participants | 374,922 |

This project is a wise use of federal funds in our estimation. It allows us to plan with some degree of rationality the development of new caregivers. The AIDS ETC network now exists so that the latest advances in research to help patients with HIV disease and to prevent the future spread of the HIV virus can be quickly communicated to the health service community. The numbers of participants speak to the fact that we have been successful in getting educational programs out to the states and cities of America.

The Administration's request of $21.0 million for FY 1991 is an increase in funding from $13.5 million in FY 1990. this increase is necessitated by the expansion during the past year to a total of 15 ETCs nationally. The addition of educational programs will take place during the coming year to key, high case prevalence areas in the United States. Further, more programs will be developed and targeted to help practitioners deal with IV Drug Abuse as it relates to the spread of HIV infection; the many AIDS issues facing minority populations in this country, and expanded clinical education opportunities for advanced AIDS care education. For these reasons, we strongly urge your support of the $21.0 million funding level in FY 1991.

Thank you for your consideration.

Sincerely,

Nathan L. Linsk

Nathan L. Linsk, Ph. D., Associate Professor
Project Director, MIDWEST AIDS TRAINING AND EDUCATION CENTER

## AIDS EDUCATION AND TRAINING CENTER FACT SHEET

- As of March, 1990, 125,000 Americans have been diagnosed with AIDS, 75,000 of these people have died. This is equivalent to total combat deaths in the Korean and Vietnam wars combined.

- As many as 10 times that many people are infected with the virus that causes AIDS. most are expected to sicken and die over the next decade. By the year 2000, more young Americans are expected to die of AIDS than were killed in the Spanish American War, World War I, World War II, Korea and Vietnam.

- This expected, casualty list will put an enormous burden on health care institutions and the care givers in those institutions.

- Because AIDS is new disease, most health care providers were not trained to care for AIDS patients. About 75% of health professionals completed their professional education prior to the first case of AIDS being recognized. Over 90% finished school without caring for an AIDS patient as part of their training.

- The need for massive retraining is obvious if we are to meet the demand for AIDS patient care.

- Since 1987, 15 AIDS Education and Training Centers (ETC's) have been established to provide AIDS education to the approximately 4,000,000 health professionals who need to be brought up to date on AIDS issues. The entire geography of the U.S. is now covered by one or another of the ETC's.

- Fiscal Year 1989-90 funding for AIDS education and training centers was approximately $14,000,000 or about $3.50 per health professional.

- Proposed funding for fiscal year 1990-91 is $21,000,000 or about $5.25 per health professional. This seems minimal given the size of the training task that needs to be done.

- Since 1987, the AIDS ETC's have done direct AIDS training for over 225,000 health professionals. In addition, another 150,000 have been reached via teleconferences and satellite education programs.

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